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# A Grounded Theory Study of How Parents Made the Decision about Residential Group Home Placement for Their Adult Child with Intellectual/Developmental Disabilities

Laura A. Prager PhD, MSN, RN, CDDN, CDCP  
Long Island University, [laura.prager@liu.edu](mailto:laura.prager@liu.edu)

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**A GROUNDED THEORY STUDY OF HOW PARENTS MADE THE DECISION  
ABOUT RESIDENTIAL GROUP HOME PLACEMENT FOR THEIR  
ADULT CHILD WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES**

by

LAURA ANN SARDINIA-PRAGER

A Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

at

Molloy College

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Dissertation Committee:

Veronica Feeg, PhD, RN, FAAN, Molloy College

Susan Vitale, PhD, RN, PNP, ANP-C Molloy College

Diane Pastor, PhD, RN, MBA, NP-C University of North Carolina, Wilmington

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2015

MOLLOY COLLEGE

DIVISION OF NURSING

The dissertation of Laura Ann Sardinia-Prager entitled A GROUNDED THEORY STUDY OF HOW PARENTS MADE THE DECISION ABOUT RESIDENTIAL GROUP HOME PLACEMENT FOR THEIR ADULT CHILD WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Division of Nursing has been read and approved by the committee:

Veronica Feeg

Veronica Feeg, Chair

Molloy College

Susan Vitale

Susan Vitale (Member)

Molloy College

Diane Pastor

Diane Pastor (Member)

University of North Carolina, Wilmington

Veronica D. Feeg

Veronica D. Feeg, PhD, RN, FAAN

Associate Dean and Director

PhD Program in Nursing

Date June 26, 2015

## **Abstract**

**Background:** The parent caregivers of a child with an Intellectual Disability/Developmental Disability (ID/DD) face lifelong challenges that may at some point involve the decision about residential group home placement of the adult child. In the course of the child's lifetime, the parents who have provided care may need to consider a safe alternative. The decision about residential group home placement of the adult child can be the result of numerous factors.

**Objective:** The purpose of this qualitative inquiry was to investigate the phenomenon of how the parent caregivers made the decision for residential group home placement for their adult child with ID/DD. Another purpose was to generate a substantive theory that describes and explains how the parent caregivers of the adult child with ID/DD made the decision for residential group home placement. This phenomenon represents a unique gap in nursing literature and nursing knowledge. Lastly, investigation of the phenomenon attempted to identify the presence of shared decision making among clinicians, nurses, the interdisciplinary healthcare team, and parent caregivers in this vulnerable population during the decision-making process.

**Method:** Using Grounded Theory methodology, the researcher investigated the phenomenon of how parent caregivers made the decision about residential group home placement for their adult child with ID/DD. Sampling was purposive, theoretical maximum variation. Using Grounded Theory, a substantive theory was constructed based on accounts of 15 community-dwelling parent caregivers as participants. Sample size was determined when saturation of the data had been reached and no additional themes emerged. The group of participants included parent caregivers who had already placed their adult child with ID/DD in a residential group home (n = 14). In addition, so the researcher could more fully understand the phenomenon, the experience of a parent who decided against residential group home placement was explored

through interview (n = 1). Mean age of the parent caregivers was 62.1, mean duration of caregiving across the group was 25.1 years, mean duration of years since placement across the group was 3.8 years.

**Results:** The basic social problem was identified as parent *caregiver readiness* to make a decision. *Parents Cannot be Caregivers Forever* was identified as the core concept/central problem of caregiver readiness. When parent caregivers identified the reality that they could not be caregivers forever based on the caregiving demands of the adult child with ID/DD, they were ready to make residential group home placement decisions for their adult child with ID/DD. Four parent caregivers' theoretical constructs were associated with the identified reality that *Parents Cannot be Caregivers Forever*: normalcy, burden, mortality, and support system. Parents go through many stages and adjustments during their lives when caring for a child with ID/DD. It is imperative that placement information be presented to parents by the interdisciplinary team at a point in time when they are receptive to accept. This research also identified that it is important for parents to communicate with other families and have interaction with supports that offer a sense of what the future may look like. By including the healthcare team and particularly nurses, parents will be able to adapt the information and participate in a shared decision-making process.

**Conclusion:** Nurses are often part of the decision-making process when the parent caregivers of a person with ID/DD are making the decision for possible placement for their adult child who is moving from the family home into a residential group home setting. Residential group home placement decisions for the adult child with ID/DD is based on the parent caregivers' readiness to identify that parents cannot be caregivers forever presented by the ID/DD diagnosis as the child ages. Greater understanding and clarity of this phenomenon will inform clinicians, nurses,

and members of the interdisciplinary healthcare team on the future creation of targeted interventions or strategies to assist with shared decision making for this unique vulnerable ID/DD population. These targeted interventions and strategies can potentially influence parent decision-making experiences positively, improve their decision-making abilities, and offer professionals direction for further research.

**Dedication**

For my wonderful mother Angela, my Angel in Heaven,

Angela Sardinia

1928-2014



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## Chapter 1: BACKGROUND AND SIGNIFICANCE

### Overview and Statement of the Problem

Parents of children with intellectual and developmental disabilities (ID/DD) face lifelong challenges that are particularly exacerbated over the child's maturation from infancy through all the developmental stages. Their parental roles are challenged by simple day-to-day activities and especially at major life events or situational changes that bring the issues of safety and support for the child into question. This becomes even more challenging as the child becomes an adult and the parents age, making it difficult to provide care and security planned for the child into the future, that may ultimately involve finding safe placement in a group home. The purpose of this proposed Grounded Theory study was to generate a substantive theory that describes and explains how parent caregivers made the decision about residential group home placement for their adult child with ID/DD. **The research question motivating this study was: How did parents make the decision about residential group home placement for their adult child with intellectual and developmental disabilities?**

### Intellectual and Developmental Disability

The federal definition of the term *Intellectual Disability/Developmental Disability* is a severe, chronic disability of an individual that is attributable to a mental or physical impairment, or combination of mental and physical impairment. The definition of *Developmental Disability* in New York State is described in Subdivision 22 of section 1.03 of the Mental Hygiene Law, as amended by Chapter 269 of the Laws of 1990. The most recent amendment of this law was enacted on July 31, 2002. The law states:

Developmental disability means a disability of a person which:

- (a) (1) is attributable to mental retardation, cerebral palsy, epilepsy, neurological impairment, Familial Dysautonomia or autism;
- (2) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such person; or
- (3) is attributable to dyslexia resulting from a disability described in subparagraph (1) or (2) of this paragraph;
- (b) originates before such person attains age twenty-two;
- (c) has continued or can be expected to continue indefinitely; and
- (d) constitutes a substantial handicap to such person's ability to function normally in society. (New York Department of Mental Hygiene, 2013)

Many people with ID/DD may experience challenges in learning as compared to others without ID/DD. They may be unable to express their thoughts clearly, have physical limitations and poor mobility, require assistance with their activities of daily living, or have multiple medical conditions and diagnoses.

### **Causes of Intellectual/Developmental Disabilities**

Many causes of ID/DD can present prenatally, during birth or thereafter. Disabilities can be the result of genetic abnormalities, improper prenatal care, or the fetus being exposed to drugs, alcohol, or other toxic substances. When the disability results during birth, it may be associated with the lack of oxygen during the birthing process, the use of forceps, or a multitude of other complications occurring during birth. Developmental disabilities caused after birth can

result from various traumatic events such as head injury or traumatic brain injury, including motor vehicle accidents, motorcycle accidents, skiing accidents, bicycle accidents, and other causes of possible head trauma. An additional factor that can result in ID/DD is substance abuse leading to damage of the brain (Office for People with Developmental Disabilities (OPWDD), 2013).

Although people diagnosed with an ID/DD may experience many limitations, many of these individuals are also “specially-abled” with astonishing abilities. In many respects, their lives may be more challenging and their future more uncertain. However, these individuals can and still do enjoy meaningful, productive lives. Individuals with ID/DD need support and encouragement from others to help maximize their abilities, recognize their unique skills and talents, and help them to become active and valuable members of the communities in which we live.

### **Intellectual/Developmental Disabilities Terminology and Service Approach**

Until recently, the terminology utilized to describe those with intellectual and developmental limitations was mental retardation. However, in 2010 President Barack Obama signed legislation requiring the federal government to replace the term *mental retardation* with *intellectual disability* in government. The utilization of ID covers the same group of people who were previously diagnosed with mental retardation. It covers the need for supportive services on the same level, type, and the duration of disability. Therefore, every individual who was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability (American Association on Intellectual and Developmental Disabilities, 2013).

Congress unanimously passed the measure known as Rosa’s Law before receiving the approval from President Obama. Rosa’s Law is named for Rosa Marcellino, a Maryland girl

with Down syndrome. Under the law, *mental retardation* and *mentally retarded* were eliminated from federal health, education, and labor policy. The terminology *intellectual disability* and *individual with an intellectual disability* is utilized instead. For many years, advocates have worked tirelessly to remove this degrading language (Degeneffe & Terciano, 2011; Fujiura, 2013).

The change has been implemented gradually over the past several years as laws and documents are revised. The use of this terminology by the federal government is now congruent with many states and some federal agencies, including the Centers for Disease Control and Prevention (CDC), already use the new language (Degeneffe & Terciano, 2011). While language consideration is important, it is nonetheless imperative to understand the abilities and disabilities of those with these conditions in order for government agencies and associated health providers to adjust services that meet their needs.

### **Criteria for ID/DD**

The *Diagnostic and Statistical Manual-5* (DSM-5) criteria for ID/DD include the onset during the developmental period (up to age 22). The person would display both intellectual and adaptive functioning deficits in areas including conceptual, social, and practical domains. In order for the person to be classified as having ID, he or she must meet the following three criteria:

1. Deficits in intellectual functioning such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience.
2. Deficits in adaptive functioning affecting activities of daily living.
3. Onset of deficits occurred during the developmental period. (OPWDD, 2013)

## **Classifications of ID/DD**

ID/DD can be specified as mild, moderate, severe, and profound. The following provides an explanation of each classification:

1. Mild: the person requires assistance with activities such as transportation, grocery shopping, and financial management.
2. Moderate: the person requires assistance with personal care, eating, dressing, and hygiene, usually requiring ongoing support and assistance.
3. Severe: the person requires support with all activities of daily living (ADLs), including meals, dressing, bathing, and elimination, therefore requiring supervision at all times.
4. Profound: the person is dependent on others for all aspects of daily physical care, health, and safety, although the individual may have some measure of participation in activities dependent on any physical impairments. (American Association on Intellectual and Developmental Disabilities, 2013)

## **Functional Limitations**

Functional limitations can occur in many aspects of the person's life. These limitations can include limitations in a person's ability to independently carry out daily activities such as eating, self-care, hygiene, grooming, financial management, reasoning, including limited consequential reasoning and decision making (OPWDD, 2013).

## **Person-Centered Planning (PCP)**

Person-centered planning (PCP) utilizes the individual's vision for the future and what he or she would like to do in the future. It helps people with ID/DD plan for their future. The goal of PCP is to move from a systems-centered model to a person-centered model. This is

accomplished with ongoing problem solving through a circle of people. This circle of people helps the individuals achieve their vision by the identification of opportunities for them and making a commitment to work together to improve the quality of each person's life. The circle of people helps individuals to participate in their community by becoming valued members of society and to develop friendships and personal relationships. The circle is usually made up of family members, friends, neighbors, co-workers, and affiliates from other groups such as church or community organizations. The circle can include service providers (OPWDD, 2013).

PCP helps people with ID/DD develop the necessary skills and talents to increase control over their own lives. It gives them assistance in empowering themselves and helps them achieve their goals to create a future. The OPWDD (2013) identified the following eight Hallmarks of a Person-Centered Planning Approach:

1. The person's activities, services, and supports are based on his or her dreams, interests, preferences, strengths, and capacities.
2. The person and people important to him or her are included in lifestyle planning and have the opportunity to exercise control and make informed decisions.
3. The person has meaningful choices, with decisions based on his or her experiences.
4. The person uses, when possible, natural and community supports.
5. Activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect.
6. The person's opportunities and experiences are maximized, and flexibility is enhanced within existing regulatory and funding constraints.
7. Planning is collaborative, recurring, and involves an ongoing commitment to the person.

8. The person is satisfied with his or her activities, supports, and services. (OPWDD, 2013)

### **Conditions Resulting in Intellectual/Developmental Disabilities**

Many causes of conditions result in ID/DD. These include a variety of genetic and disease/disorder sources of intellectual and developmental problems. The following briefly describes five of the major categories of conditions that are often associated in people with Developmental Disabilities (DD). These include intellectual disabilities, cerebral palsy, Down syndrome, neurological impairments, and Autism Spectrum Disorders (ASD).

These conditions are commonly seen in persons with ID/DD, as well those in residential group homes. Persons with these conditions present unique challenges to the interdisciplinary team providing support and services to both the individual and family.

**Intellectual disability.** More than 280,000 people in New York State are thought to have intellectual disabilities (ID). There are over 13,360 adults with developmental disabilities in Nassau County, New York. Of those identified individuals, 1,700 reside in community residences, 5,300 people receive individual and family support services, and 3,600 are enrolled in day services. A person with ID presents with a slower pace or delays in his or her ability to learn and difficulty in application of what he or she has learned. The diagnosis may result from a variety of circumstances including prenatal conditions, genetic defects, or being socially deprived. It is important that assistance and supports are provided early in life for maximal benefit. In the early years of the person's life, the family can be provided with education, counseling, and training. With the proper supports as he or she ages, the person with ID/DD can achieve and contribute as an active member in the community. Current practice when supporting a person with ID/DD in the community involves person-centered planning (PCP). PCP is a



structured service delivery for the person with ID/DD that includes an individualized plan for both formal and informal support recognizing the “person” and not the disability at the center of the plan (OPWDD, 2013). ID refers to and includes the cognitive aspect of the definition related to thought process. Because ID and DD usually exist together, occurring simultaneously, professionals often care for people with both types of disabilities (American Association on Intellectual and Developmental Disabilities, 2013).

The term *developmental disabilities* (DD) encompasses and includes the term *intellectual disabilities*. However, also included are other disabilities that are evident during childhood. DD refers to chronic, lifelong conditions that can be physical, cognitive, or both appearing before age 22 (American Association on Intellectual and Developmental Disabilities, 2013).

***Determination of intellectual disability.*** The diagnosis of intellectual disability is not just determined by an Intelligence Quotient (IQ) test. Three important criteria are considered for the classification and evaluation of intellectual disability. The three criteria are the following:

- Significant limitations in intellectual functioning
- Significant limitations in adaptive behavior
- Onset before age 18

The IQ test is an instrument that measures intellectual functioning. Intellectual functioning refers to mental ability in areas such as learning, reasoning, and problem solving. A test score between 50 and 70 indicates a limitation in intellectual functioning (Cheung, 2013).

A multitude of other tests is used to determine limitations in intellectual functioning.

These tests cover three types of skills:

- Conceptual
- Social skills

- Practical skills

The conceptual skills assessed can include language, literacy, money, time, and number concepts as well as self-direction. When assessing social skills, the areas being evaluated are interpersonal skills, social responsibility, self-esteem, gullibility, naïveté, social problem solving, and the ability to follow rules, obey laws, and avoid being victimized. The other skill areas are those of practical skills involving activities of daily living, personal care occupational skills, healthcare, travel, transportation, safety, use of money, and use of a telephone.

When determining intellectual disability, in addition to assessing intellectual and adaptive behavior, professionals should also take other factors into consideration. Professionals need to include assessment of community environment, linguistic diversity, and the different ways people communicate, move, and behave across cultures. The importance of classifying individuals with intellectual disability is to custom-design services and supports for each individual (American Association on Intellectual and Developmental Disabilities, 2013).

**Developmental disabilities.** Impairments in the areas of independence and social responsibility such as communication, social participation, academic or occupational functioning, and personal independence in the home and community are characteristics of a developmental disability. DD is a severe, chronic disability that includes mental or physical impairment or a combination of mental and physical impairments. DD is usually seen before the individual reaches age 22 and can result in functional limitations in three or more of the following areas: a) major life activity; b) self-care; c) receptive and expressive language; d) learning; e) mobility; f) self-direction; g) capacity for independent living; and h) economic self-sufficiency. The person requires individually planned services that are of lifelong or extended duration.

Developmental disabilities may occur anytime from prenatal up until the age of 22. These are different from “developmental delays,” that show up as a delay in one or more areas of growth or skill. A developmental disability condition may cause a person to have physical difficulties and limitations, or difficulty learning and growing.

Eligibility for OPWDD supports or services requires that the developmental disabilities are defined as the following qualifying conditions that include: intellectual disability (known as “mental retardation” in Mental Hygiene Law), autism, cerebral palsy, epilepsy, familial dysautonomia, and neurological impairment includes injury, malformation, or disease involving the central nervous system (OPWDD, 2015).

**Cerebral palsy.** Cerebral palsy can typically be the result of a brain injury before, during, or after birth. More than 24,000 New York residents have cerebral palsy. Individuals with cerebral palsy typically have trouble meeting developmental milestones. The term *cerebral palsy* encompasses a variety of conditions that affect the brain as well as difficulty with movement. People with cerebral palsy may have difficulty with movement, speech, vision, learning, and may have seizures. Because of the presenting symptoms and often-extreme difficulty with speech, those with cerebral palsy are often mistakenly thought to have ID by others who meet them (United Cerebral Palsy, 2013).

Some of the causes of cerebral palsy include infections, pregnancy problems, premature birth, multiple births, severe jaundice (kernicterus), strokes, genetic disorders, and child abuse.

Appropriate prenatal care and treatment as well as the recognition of infections may also help to prevent cerebral palsy (Dodge, 2008).

Children and adults with cerebral palsy may have a variety of physical and functional limitations. They may require the use of sophisticated adaptive equipment that will assist with movement and communication. Additional supports for individuals with cerebral palsy would include the professional services of physical, occupational, and speech/language therapists (Kriger, 2006).

People with cerebral palsy can experience a decrease in muscle strength after many years of having no change in motor functioning. It is estimated that some 500,000 children and adults in the United States present with one or more symptoms of cerebral palsy. Currently about 8,000-10,000 babies and infants are diagnosed with the condition each year (Centers for Disease Control and Prevention, 2015). Other changes seen as these individuals age include an increase in osteoporosis, osteoarthritis in joints, contractures, spasticity, seizures, fatigue, and a decrease in stamina. Contractures are a loss of joint range that is exhibited by the person with cerebral palsy. Spasticity in an individual with cerebral palsy is defined as a motor disorder that occurs from the stretch reflex that is overexcited. The resulting presentation is the individual displays tendon jerks and stiff stretch reflexes (Chiu, Ada, Butler, & Coulson, 2011). Individuals diagnosed with cerebral palsy can experience difficulties in swallowing, resulting in possible choking or aspiration pneumonia.

**Down syndrome.** Down syndrome (also called Trisomy 21) is a genetic disorder. Nearly 5,000 babies are born with Down syndrome in the United States each year, translating to 1 in every 733 births, and it is the leading cause of cognitive impairment. Down syndrome is associated with mild to severe intellectual disabilities, developmental delays, characteristic facial

features, and low muscle tone in early infancy (Morton, 2011). Many individuals with Down syndrome also have associated medical issues including but not limited to heart defects, leukemia, early-onset Alzheimer's disease, and gastrointestinal problems.

Life expectancy for individuals with Down syndrome has dramatically increased over the past few decades as medical care and social inclusion have improved. A person with Down syndrome in good health will, on average, live to age 60 or beyond. Sometimes a person inherits an extra chromosome from one of the parents. In Down syndrome, an individual most often inherits two copies of chromosome 21 from the mother and one chromosome 21 from the father for a total of three chromosomes 21. Because Down syndrome is caused by the inheritance of three chromosomes 21, the disorder is also called Trisomy 21. About 95% of individuals with Down syndrome inherit an entire extra chromosome 21 (Morton, 2011).

For a specific chromosome, the causes of a trisomy are the result of a misdivision in the sperm or the egg prior to conception. There is nothing anyone can do to prevent a trisomy. It is an accidental occurrence that happens before conception in either the egg or the sperm. It is not known what causes a trisomy to occur in Down syndrome (Tingey, 1988).

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one individual. Some common characteristics include a flattened appearance to the face, a high and broad forehead, a proportionately smaller head, an upward slant to eyes/narrow slit to eyes, a small depressed nose, small ears and oral cavity, a large protruding tongue, short neck, arms, fingers, legs and toes, enlarged heart, language deficits, poor muscle tone (hypotonia), loose joints (hyperflexibility), weak reflexes, poor impulse control, a tendency to be overly affectionate, and an increased attention towards food and eating (Tingey, 1988).

Early intervention services are necessary for the basic physical, cognitive, language, social, and self-help skills that lay the foundation for future progress. Medical specialists, including cardiologists and gastroenterologists, are important for optimal health. In addition, physical therapy may be needed to facilitate the use of gross motor skills. Social skills training is provided to teach, enhance, and integrate individuals into common social exchanges. These individuals also benefit from speech and language therapy. Occupational therapy services help facilitate the use of fine motor skills and to strengthen and coordinate the timing of muscle movements. Appropriate behavior intervention services including applied behavior analysis (ABA) therapy or behavior modification is used to decrease challenging behaviors and increase adaptive and replacement behaviors. Specialized educational services can be provided to assist specific learning needs (National Association for Down Syndrome, 2013).

**Neurological impairments.** Neurological impairments are a group of disabilities including disorders of the brain and central nervous system that considerably limit a person's development, understanding, memory, attention span, fine muscle control, use of language, or ability to adjust to new situations. Generally, these impairments begin during childhood or adolescence. People with neurological impairments may experience a variety of learning difficulties or social behavior problems. They also may have special care needs because of problems in memory, conversation, organization, and impulse control.

Approximately 34,000 people in New York State are thought to have some type of severe neurological impairment. Neurological impairments can be the result of an acquired or inborn condition. Many of these people learn to compensate for their disabilities and lead fulfilling lives to varying degrees (National Institute of Neurological Disorders and Stroke, 2013).

**Epilepsy.** Epilepsy is a general term that applies to different nervous system disorders that can result in seizures. Estimates of the number of people with epilepsy in the United States range from 1.4 to 2.7 million people. Children with developmental disabilities are found to be at an increased risk for epilepsy. In many situations, the medical reason for the developmental disability is often also the cause for the seizure disorder. Often the child with ID/DD may, in addition, present with a psychiatric problem. This complicates the treatment because many of the children with ID/DD may already be on anti-epileptic drugs (Depositario-Cabacar & Zelleke, 2010).

Seizures may cause an involuntary change in body movement or function. It is not unusual for people with epilepsy to develop behavioral and emotional problems in addition to their seizure activity. At this time there is no cure for epilepsy. Prolonged or repeated seizure activity can lead to brain damage and, in some cases, result in sudden death. The term *epilepsy* can be used interchangeably with *seizure disorder*. The spectrum of brain disorders can vary from life threatening to much less serious and benign. There are over 20 different types of seizures, and multiple seizure types are seen in children with developmental disabilities including generalized tonic-clonic, absence, myoclonic, tonic, atonic, and focal (Depositario-Cabacar & Zelleke, 2010).

A neurologist most often generates the diagnosis of epilepsy where a medical history is obtained, a neurological examination is completed, and a description of the seizure activity is provided, including how long it lasts, what precipitates it, any aura (warning signs prior to the seizure activity), level of consciousness, and a description of the postictal period (after the seizure), which are all important factors in diagnosing the seizure type. Diagnostic testing can include a continuous 24-hour electroencephalogram (EEG) and a brain magnetic resonance

imaging (MRI). Additionally, to diagnose the presence of seizures in the child with ID/DD, further diagnostic testing could include metabolic and genetic testing (Depositario-Cabacar & Zelleke, 2010).

The goal of treatment by the medical community for the epileptic child with ID/DD is control of the seizures. It must be a careful balancing act to gain optimal seizure control with the appropriate use of medications while causing minimal side effects from the drugs prescribed. Cognitive and behavioral adverse effects from the use of antiepileptic drugs (AED) are more likely to occur in children with ID/DD. Therefore, it is imperative that the side effects of the medications used are carefully monitored. In addition to pharmaceutical therapy, there are other treatment options including ketogenic diet, surgical techniques with implantation of a vagus nerve stimulator (VNS), or epilepsy surgery. These other treatment modalities are generally considered after a child has failed to have positive treatment effects from at least two antiepileptic drugs (AEDs). The goal of treatment should be to improve the quality of life with appropriate seizure control without or with minimal side effects from medication therapy (Depositario-Cabacar, & Zelleke, 2010).

The possibility of seizures can affect the independence and recreational activities in which the individual may participate. The individual with ID/DD residing in a residential group home may be required to wear a helmet at all times to reduce the risk of possible head trauma with the onset of an unexpected seizure. Additionally, the side effects of many of the AEDs used to treat children with epilepsy and ID/DD are sometimes sedating; therefore, these side effects can impact their quality of life.

**Familial dysautonomia.** Familial dysautonomia (FD) is an inherited genetic disease with an autosomal recessive pattern. In an autosomal recessive pattern, both copies of the gene



in each cell contain the mutation. It is possible for the parents of a person with familial dysautonomia to carry a copy of the mutated gene, but generally they do not display signs and symptoms of the condition. The gene associated with the cause of familial dysautonomia is the IKBKAP gene. The protein IKK complex associated protein (IKAP) is made by the instructions provided by the IKBKAP gene. The mutation interrupts the instructions given by the IKBKAP gene to make the protein IKAP. The lack of instructions provided causes a decrease in the amount of normal KAP protein produced. Although some cells produce a normal amount of protein, others, mostly the brain cells, produce very small amounts of the protein. The activities in the brain cells are impacted by the lack of protein resulting in the signs and symptoms of familial dysautonomia (Anderson et al., 2001; National Institute of Health, 2015).

Familial dysautonomia is present at birth in both male and female infants. FD is most common in people of Jewish descent from Ashkenazi (Central or Eastern European) and affects about 1 in 3,700 individuals. Thirty-three percent of those affected live in the New York metropolitan area. FD causes dysfunction of the autonomic and sensory nervous systems. The dysfunction is a result of an incomplete development of the neurons of these systems. The average age of the FD population is children approximately 15 years old. Those children born with FD have a 50% chance of surviving to 40 years of age. The primary causes of death result from pulmonary complications or sudden death due to autonomic instability. There is no cure for FD and the goal is to treat symptoms while preventing complications (Slaughaupt & Gusella, 2002).

The symptoms of FD may vary, including insensitivity to pain, unstable blood pressure and body temperature, and absence of overflow tears, frequent pneumonia, and poor growth. Individuals with FD can experience cyclical vomiting accompanied by extremely high blood

pressure and increased heart rate, sweating, and fever. They may experience orthostatic hypotension that can cause dizziness, blurred vision, or fainting. Conversely, they can also have episodes of high blood pressure. These “autonomic crises” are one of the most devastating symptoms of this disease, often requiring hospitalization, and they are the most common cause for sudden death (Carroll, Kenny, Patwari, Ramirez, & Weese-Mayer, 2012).

FD has been associated with an increased frequency of learning disabilities. However, early language and learning interventions have been extremely successful in treatment. There is no cure for FD. Treatments are limited to supportive interventions that minimize problems and promote function. Supportive therapies include medications to maintain and regulate cardiovascular, respiratory, and gastrointestinal function. Surgical interventions include fundoplication, gastrostomy, spinal fusion, and tear duct cauterization. Also utilized are therapies including physical therapy (PT) and occupational therapy (OT) to promote strength and speech development. However, by adulthood, individuals with FD often have increasing difficulties with balance and difficulty walking unaided. Other problems that may appear in adolescence or early adulthood include lung damage due to recurrent infections, poor kidney function, and decreased vision due to the atrophy of optic nerves (Slaughaupt & Gusella, 2002).

**Autism Spectrum Disorder.** Autism affects an individual’s social interaction and communication ability. Autism Spectrum Disorders (ASD) includes autism, Asperger’s syndrome, Rett syndrome, and childhood disintegrative disorder. In 2013, the *DSM-5* placed autism, Asperger’s syndrome, and other pervasive developmental disorders under the diagnosis of ASD. ASD also includes autistic disorder, pervasive developmental disorder (PDD), not otherwise specified (PDD-NOS, including atypical autism), and Asperger’s syndrome. The associated characteristics can include: challenging behaviors, affective symptomologies, learning

disabilities, intellectual impairments, sensory disorders, and stereotypical motor or verbal behaviors. Diagnosis of ASD can sometimes occur later in life and is usually associated with social, emotional, and learning difficulties. Diagnosis is similar to that of younger children with specific evaluations completed by professionals. Being diagnosed later in life can be a source of relief for many who have been struggling for years, never knowing or understanding the root of their social issues. Once diagnosed, it also allows the person to access services to achieve their potential and improve their quality of life (Gaus, 2011).

There is no known cause for ASD, and the incidence of autism is still under debate. Several researchers have completed genetic screens that have identified several genomic regions containing genes that could be associated with autism (CDC, 2013).

ASD occurs in all racial, ethnic, and socioeconomic groups. The thinking and learning abilities of people with ASD can vary from gifted to severely challenged. The common traits and symptoms include difficulty communicating and interacting. One third of those with ASD are nonverbal. For those who are verbal, the repeating of words (echolalia) may be present. Those diagnosed with ASD may present with a poor attention span. Some individuals have multiple diagnoses of attention deficit hyperactivity disorder (ADHD) or attention deficit disorder (ADD). Other characteristics may include poor understanding and interpretation of both verbal and nonverbal social cues such as body language, voice pitch, tone, inflection, facial expression, sarcasm, and jokes. Those with ASD may also have difficulty maintaining eye contact; difficulty with change or transition; displaying extremes of emotion such as love and hate; ritualistic, self-stimulatory behaviors (such as hand flapping); self-injurious behaviors (hitting or biting oneself); obsessive compulsive disorder (OCD) like behaviors such as spinning; sensory integration dysfunction displayed as the avoidance of noise, touch, or difficulty eating

certain textures of food; and a different level of pain tolerance. Seventy percent of those diagnosed with ASD also have intellectual disabilities (CDC, 2013).

The following statistics for ASD were reported by the CDC in 2015:

1. About 1 in 68 children (or 14.7 per 1,000 8 year olds) were identified with ASD. It is important to remember that this estimate is based on 8-year-old children living in 11 communities. It does not represent the entire population of children in the United States.
2. This new estimate is roughly 30% higher than the estimate for 2008 (1 in 88), roughly 60% higher than the estimate for 2006 (1 in 110), and roughly 120% higher than the estimates for 2002 and 2000 (1 in 150). We do not know what is causing this increase. Some of it may be due to the way children are identified, diagnosed, and served in their local communities, but exactly how much is unknown.
3. The number of children identified with ASD varied widely by community, from 1 in 175 children in areas of Alabama to 1 in 45 children in areas of New Jersey.
4. Almost half (46%) of children identified with ASD had average or above average intellectual ability (IQ greater than 85).
5. Boys were almost 5 times more likely to be identified with ASD than girls. About 1 in 42 boys and 1 in 189 girls were identified with ASD.
6. White children were more likely to be identified with ASD than African American or Hispanic children. About 1 in 63 White children, 1 in 81 African American children, and 1 in 93 Hispanic children were identified with ASD.
7. Less than half (44%) of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

8. Most children identified with ASD were not diagnosed until after age 4, even though children can be diagnosed as early as age 2.
9. African American and Hispanic children identified with ASD were more likely than White children to have intellectual disability. Children identified with ASD and intellectual disability have a greater number of ASD symptoms and a younger age at first diagnosis. Despite the greater burden of co-occurring intellectual disability among African American and Hispanic children with ASD, these new data show that there was no difference among racial and ethnic groups in the age at which children were first diagnosed (CDC, 2015).

Psychotropic and antipsychotic medications may be effective in treating symptoms. Antipsychotics, antidepressants, selective serotonin reuptake inhibitors (SSRI), and stimulants have been used and have been successful in treating symptoms. Caring for an individual with ASD is complicated, especially for caregivers who may be unfamiliar with the personal needs and routines of the adult with ASD. The familiarity with these behaviors for parents of adult children with ASD helps them understand caring issues. When faced with changing situations, parents worry about what those new situations may bring.

When caring for an individual with ASD, it is important to provide daily schedules to enable the individual to predict the next task or activity. When speaking to a person with ASD, limited vocabulary should be used. The person with ASD often has difficulty transitioning from one task to another and should be provided with transition warnings in addition to warnings about potentially stressful situations. During interactions with others, the ASD individual should be provided an “escape route” in cases where the person may become overstimulated and need to leave. It is important to allow for an increase in the individual’s personal space whenever

possible (Gaus, 2011). These are among many concerns that caregivers of individuals with ID/DD on the autism spectrum are concerned with in treatment and placement decisions.

**Autism.** Autism can be diagnosed in children as early as six months. However, most do not receive a diagnosis until about two years, when parents realize their child has verbal communication challenges. Diagnosis can also occur later in life providing the person the opportunity to access the necessary services and support (Grandin, 2013).

At this time there is no specific medical test that can diagnose autism. Rather, professionals including physicians and psychologists that are specially trained administer autism-specific behavioral evaluations. Diagnostic evaluation often involves an interdisciplinary team including a pediatrician, psychologist, speech and language pathologist, and occupational therapist.

Many complex issues surround an autism diagnosis. Professionals, scientists who study autism, people with autism, and people caring for those with autism have controversy on many issues. These issues include the terms that should be used when describing autism, what causes autism, and what constitutes a single diagnosis or a group of syndromes. Professionals debate whether this is a disease that needs to be cured or rather a set of unique characteristics a person possesses that should be respected. It appears that these debates and issues will continue for many years (Gaus, 2011). The recent change in the *DSM-5* reinforces how there continues to be tremendous complexity in diagnosis and the controversy will continue years to come.

Individuals with autism need a variety of services and supports. Speech therapy (ST) is often used to teach communication either verbally, through sign language, or with a picture exchange system (PES). Behavior intervention services (BIS) may be helpful with the use of applied behavior analysis therapy (ABA) or behavior modification used to decrease challenging

behaviors and increase adaptive and replacement behaviors. Occupational therapy (OT) services are used to treat symptoms of sensory integration dysfunction. Additionally, social skills training is provided to teach, enhance, and integrate individuals into common social exchanges. Specialized educational services can be provided to assist specific learning needs.

### **Conditions Resulting in ID/DD: Genetic Causes**

**Smith-Magenis syndrome.** Osorio et al. (2015) described Smith-Magenis syndrome as a distinct and clinically recognizable genetic disorder affecting many parts of the body. It is characterized by mild to moderate intellectual disability, delayed speech and language skills, distinct facial features, sleep disturbances, and behavioral problems.

**Smith-Lemli-Opitz syndrome.** Smith-Lemli-Opitz Syndrome is an autosomal recessive syndrome gene mutation that is associated with many congenital anomalies, intellectual impairment, growth delay, behavioral problems, low levels of plasma cholesterol, and elevated sterol precursors (Kelly, Tuli, Stern, & Giordano, 2015).

**Rett syndrome.** Rett syndrome is a complex neurological disorder resulting from a genetic fault that occurs mostly in females and affects them throughout their lives. Often there is normal early growth and development followed by a decline and slowing of development. In Rett syndrome, behaviors are often autistic-like; other characteristics include walking on toes, sleep problems, teeth grinding, wide-based gait, hyperventilation seizure disorders, cognitive disabilities, apnea, and slowed growth. There is no cure for Rett syndrome and treatment involves treating the symptoms. Life expectancy is generally not expected beyond age 40 (Briggs, 2014).

**Prader Willi syndrome.** Prader Willi syndrome was first identified in 1956 and can affect both genders. The incidence of Prader Willi syndrome is 1 to 15,000 to 1 to 25,000 live

births (Avidan & Kaplish, 2010). Individuals diagnosed with Prader Willi syndrome exhibit hypotonia, hyperphagia, obesity, hypogonadism, and mild intellectual disabilities (Landsman, 2014).

**Agenesis of the corpus callosum.** Agenesis of the corpus callosum is a congenital condition that occurs during the early prenatal period resulting in an abnormality of the brain. The corpus callosum does not develop as it should and the condition can occur as an isolated condition, or in addition to other physical and medical conditions or other brain abnormalities. It is characterized by a partial or complete absence (agenesis) of an area of the brain that connects the two cerebral hemispheres. The condition can result in subtle developmental and cognitive challenges to more severe disability (Yoo & Hunter, 2013).

### **Uniqueness of the ID/DD Population**

Most individuals with (ID/DD) require some level of assistance throughout their lives. Because of pre-existing conditions and predisposing circumstances, the aging process for those with ID/DD can be a more difficult process. Individuals with ID/DD are more likely to develop chronic health conditions at a younger age than the general population adults. The early development of chronic medical conditions results from biological factors related to syndromes coupled with developmental disabilities (Yamaki, 2005). The life expectancy of the person with ID/DD continues to increase. Therefore, the number of older adults with ID/DD continues to expand. Community agencies and families now face the challenge of providing supports and services as these adults experience age-related changes and medical conditions. When these changes occur in their early adulthood, they may be more likely to still be living with their aging parents. The aging parents of the adult child with ID/DD may have debilitating medical or neurological diagnoses of their own. They themselves could simultaneously be facing the



necessity to place a spouse in an assisted living facility or nursing home. The aging parent could be a widow who is unable to provide the care alone. These parents may no longer physically or emotionally be able to care for the adult child with ID/DD.

Individuals with ID/DD are eligible to receive support services until the age of 21 through the Individuals with Disabilities Education Act (IDEA, PL 101-476). The public educational system is no longer responsible for securing services and support once the individual “ages out.” The responsibility then shifts to the individual, parent caregivers, or other caregivers. Once an adult child “ages out” of the educational system, he or she could possibly be eligible for some type of day programming activities or vocational setting. Unfortunately, the services for the adult child with ID/DD tend to decrease drastically at this milestone.

This vulnerable group of aging persons with ID/DD requires increased awareness from the public, clinicians, and interdisciplinary healthcare team. The interdisciplinary healthcare team must be cognizant of the aging of the parent caregivers, as well as the increase in the life expectancy of persons with ID/DD due to advances in medicine and technology. Decisions for their future healthcare and possible residential group home placement may require careful consideration and identification by clinicians and the interdisciplinary healthcare team.

Changes in demographics, including increased life expectancy for people with developmental disabilities, the current economic climate requiring both parents to work outside the home, and the aging of the parent caregiver, have resulted in the demand for placement opportunities to likely outpace the supply for decades to come. These changes suggest to professionals that there are converging issues presenting current and future challenges in the care of the ID/DD population. This research explored the salient considerations and concerns that parent caregivers expressed in their decision process to place their adult children in a group

home or alternative. Identifying and understanding their needs and worries may help inform clinicians and the interdisciplinary healthcare team.

### **Study Purpose and Research Question**

Individuals with ID/DD are faced with a variety of needs that require a combination of cognitive, social, and health services. The community consisting of those with intellectual and developmental disabilities is a population that can best be served by a wide range of interdisciplinary providers. The individual with ID/DD needs a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are lifelong or extended in duration and are individually planned and coordinated. Shared decision making considers a patient's preferences when developing a treatment plan to accomplish the person's health goals (Charles, Gafni, & Whelan, 1997). This is a joint process among clinicians, nurses, the interdisciplinary team, and patients. When parents are making the decision for placement of their adult child with ID/DD from their family home into a residential group home setting, nurses are often part of the decision-making process. Nurses are one of the first contacts parents have with the organization that may eventually provide group home placement, services, and support to their adult child with ID/DD. During the screening process at this initial meeting, the beginning of the long-term relationship occurs. It is at this time when the organization provides support services to the ID/DD population. The interdisciplinary team identifies the needs of the adult child. The nurse is instrumental during the screening process and is crucial in the future development of a treatment plan to appropriately and safely support and meet the needs of the individual with ID/DD. The possible eventual need for placement may be a result of numerous factors that were explored through this research.

The researcher investigated the phenomenon using Grounded Theory methodology in an attempt to answer the research question of how parents made the decision for residential group home placement for their adult child with ID/DD. These insights from the past will help inform professionals to plan for supporting parents of adult children make decisions in the future.

### **Research Purpose**

The purpose of this qualitative inquiry was to generate a substantive theory that describes and explains how parents made the decision for residential group home placement for their adult child with ID/DD. In addition, the investigation of the phenomenon attempted to identify the degree of shared decision making among clinicians, the interdisciplinary healthcare team, and parent caregivers who serve this vulnerable population during the decision-making process.

**ID/DD parent caregivers: Impact of providing care.** Davys and Haigh (2007) identified that parents of children with learning disabilities, like parents of children with ID/DD, have concern for their children as they age into adulthood. This is a universal phenomenon. However, as the child with ID/DD ages, parents worry about their future living accommodations needs due to their child's continuing dependency. They worry about where their child with disabilities may live when the parents are not able to give support at home. Parents also have worries about what the siblings of the person with ID/DD may have to do in the future when the parents are gone and no longer able to assist in the care (Davys & Haigh, 2007).

Some research literature has identified that there are family dynamics involved in the decision situation that may provide insight into the stressors which exist in making a placement decision (Penrod & Dellasega, 1998) or residential group home placement of the adult ID/DD child. The dynamics became evident through the careful investigation of the process of how

parents made the decision about residential placement. The insights contributed to understanding the phenomenon of the unique family dynamics operating in these families.

In a study conducted by Llewellyn, Dunn, Fante, Turnbull, and Grace (1999), the researchers explored family factors influencing out-of-home placement for young children with ID/DD. One of the factors influencing families that had decided on placement for their young child with ID/DD was that the child had become a burden, and in order for the family to survive, the only solution was placement of the child. The precipitating factor was the concern for the family members individually and the family as a whole. The parent's decision making was also influenced by a concern for the child's siblings. Other factors identified for parents making decisions included: a) if the services the child had been receiving were cancelled, b) marital status disruptions resulting from the care demands of the child, and c) a marked increase in disruptive behaviors exhibited by the child.

The ambiguities that parents experience when raising a child with severe or profound developmental disabilities were explored in a study conducted by Olsen-Roper and Jackson (2007). They described that parents experience an ambiguous loss when they experience a death of the dreams they had for the child who was present in a physical sense, but absent in a psychological capacity. They identified that parents experienced role ambiguity in regard to the ability to work on their relationship as a couple and other parent-child relationships. Role ambiguity was a result of the caretaking demands of the child with severe or profound developmental disabilities. Additionally, siblings were often needed to perform functions of caretaking beyond normal expectations. After a placement decision had been made, the parents continued to experience role ambiguity when they were required to turn over their caretaking roles to someone else. Parents also feared that there was a possibility that their child could lose

the placement. Although not physically living with the parents, the child remained psychologically present in their minds. The ambivalent feelings regarding their placement decision continued for the parents even after the child was placed.

Caring responsibilities increase over time for a child with severe developmental disabilities and challenging behaviors, as identified by Hubert (2010). Mothers are often the primary caregivers of a child with ID/DD and the caregiving responsibilities increase over time becoming even more time consuming, with increased concerns, as their children became adults. The commitment involved in caring for the child often results in physical and emotional fatigue and exhaustion (Tadema & Vlaskamp, 2009). The relationships of marriage, friends, and family are often impacted from the level of caregiving responsibilities resulting in isolation. Mothers also reported that the amount of services and the support of external services declined as their child with ID/DD moved into adult services (Hubert 2010).

As previously noted, children with ID/DD are living longer, which directly affects the support needs of the parents from the interdisciplinary team. Parenting a child with ID/DD can be a positive experience that is correlated with the support parents receive from immediate and extended family, at the time of diagnosis and as the child ages (Bruns & Foerster, 2011). In a study of parents of children with rare trisomy conditions, parents reported positive support experiences with spouses and difficulties with extended family members as well as maternal and paternal grandparents. As reported by parents, support received in caring for the child with ID/DD is viewed as extremely important (Tadema & Vlaskamp, 2009).

Parent caregivers of adult children with ID/DD have unique and distinct needs when making residential group home placement. These special needs are a direct result of their caregiving situation.

### **Significance of Study**

A greater understanding of how parents made the decision for residential group home placement for their adult child with ID/DD could help clinicians and the members of the interdisciplinary healthcare team, including nurses, better assist and support the parents with their decision. Further clarity regarding the process of the decision can identify potential strategies and resources (future nursing interventions) from which the parents may benefit. Understanding this phenomenon may also help to identify what point in the life of the person with ID/DD, and in the life of the parents, is best to begin the planning process.

Additionally, it may also help determine what possible supports and strategies could assist the parents with achieving confidence and satisfaction with their decision to place or not to place their adult child with ID/DD in a residential group home. Dellasega and Mastrian (1995), in their study of institutionalizing an elder, suggest that the healthcare professional must become aware of the consequences of placement so that increased tailored support of the family can be offered both pre and post placement. Although Dellasega and Mastrian's study examined the elder population, this researcher identified similar needs of parents making decision placement for their adult child with ID/DD.

Due to advances in medical care and treatment, the majority of parents can expect to be survived by their son or daughter with ID/DD (Bittles et al., 2002; Janicki & Wisniewski, 1985). The average age of death for people with developmental disabilities has increased to equal the average age of death of people without impairments (Coppus, 2013). The demand for care and placement in residential group homes will be greater than the available supply of homes. There are changes in the family demographics and an increase in the life expectancy of people with ID/DD. In addition, resources for residential group homes are limited, and the ID/DD population

and the general elderly population are competing for resources (Parish & Lutwick, 2005). Parents who have been the primary caregiver may be unfamiliar with community supports available as well as unsure about how to navigate the social service system (Smith, Fullmer, & Tobin, 1994). Expanded training for nurses, along with new interventions and family-centered approaches when working with people with developmental disabilities, can help nurses better assist parents with placement decisions.

With the growing life expectancy, the number of adults with ID/DD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 (Bittles et al., 2002). Braddock, Hemp, and Rizzolo (2008) reported that over 75% of people with ID/DD live with their families. More than 21% of family care providers are over 60 years of age with another 38% between ages 41-59 years old. It was estimated from a report of trends up to 2008 that 115,000 of these families nationally with children with ID/DD will be faced with long residential group home waiting lists (Lakin, Larson, Salmi, & Scott, 2009) as their parents age as well.

Moving from home is a major life disruption in the general population. It is often seen as a significant point in a person's life, representing marriage, a new job, "being on your own," or moving in with a friend or partner. People move out of their homes for negative reasons as well, such as family conflict, change in health status, and death of a family member. The change of moving from one location to another affects the well-being of the person as well as having significant ramifications for all those involved in the process. These life-changing events comparably affect people with ID/DD as well as their parents who must be supported before, during, and after the decision and process of placement (Alborz, 2003). Transitions for people with ID/DD and their parents are equally significant, and may be a far more challenging

transition. It is possible that parents feel that caring for a son or daughter with learning disabilities is a difficult responsibility, yet they want to provide care as long as possible. It is possible that parents may look at placement as a different kind of caregiving rather than giving up as care providers. Research of this phenomenon could possibly lead to greater understanding of the parents' beliefs surrounding their decision.

### **Researcher's Perspective**

Through my professional career of 32 years as a registered nurse, and a Certified Developmental Disabilities Nurse (CDDN) working in this specialized area of ID/DD nursing for over 23 years, I have observed how difficult these issues can be. It has been my experience that these parents are often isolated, lacking the necessary information and support during the decision process. They are uncertain how to actually make the decision with confidence and clarity. On numerous occasions I have observed parents who are unaware of their options. They lack information about services and supports available for their child with ID/DD. Often, they are unsure about when is the appropriate time to begin consideration and discussion about possible placement. In many situations parents are unclear about who is the appropriate person with whom to discuss their questions. This delay often results in waiting until a crisis or point in time when the decision for residential placement must occur immediately. They find themselves without any possibility for the sharing of information. This has led the researcher to seek information in the literature that could possibly help inform clinicians and members of the interdisciplinary healthcare team, including nurses, to guide a better process. However, gaps are present in the literature. Nursing knowledge is lacking to address this phenomenon. Information could help to determine at what point in time discussions with parents should begin that appropriately assist parents with the decision-making process. Decision making at various points



in time throughout the lives of both the parents and child with ID/DD is complex and emotional, and needs to be understood in the context of placement decisions that are shared among the individuals most affected.

### **Developmental Disabilities Nurses Association**

The Developmental Disabilities Nurses Association (DDNA) is a national organization of nurses who specialize in ID/DD nursing. The association was incorporated in 1992 and is a 501(c)(3) not-for-profit nursing specialty organization that is committed to advocacy, education, and support for nurses who provide services to individuals with ID/DD. The goal of the association is to encourage and promote nursing knowledge and expertise in the care of individuals with ID/DD.

The DDNA offers certification in the specialty of ID/DD, as well as promoting and supporting opportunities for professional networking among members through regional chapters and educational opportunities (Developmental Disabilities Nurses Association, 2015).

### **Certified Developmental Disabilities Nurse**

The Developmental Disabilities Nurses Association (DDNA) can certify nurses as a certified developmental disabilities nurse (CDDN) in the specialized area of developmental disabilities. The CDDN has the level of expertise, education, and understanding to better assist parents of children with ID/DD in the placement decision process. Findings from this research study will further inform the CDDN about placement decision strategies and interventions to be utilized when working with parents. The certification represents a national recognition in the specialized area of ID/DD nursing. For the nurse practicing in the field of developmental disabilities, certification also documents that the nurse possesses special knowledge to meet the complex nursing care needs of the individual with ID/DD. A CDDN is an exemplar of

specialization that benefits the profession of nursing and the specialized area of caring for the person with ID/DD. Certification as CDDN represents a recognized level of expertise, experience, achievement, and competence beyond licensure. This specialty certification attests that a nurse is competent and knowledgeable in the specialized field of ID/DD nursing. The elevated competency represented by certification could possibly provide an increased level of understanding of the many concerns surrounding the individual with ID/DD, as well as the challenges faced by their parents. A CDDN understands and complies with the standards of the professional organization, practices professionally by those standards, and is an example of excellence. The CDDN completes continuing education in the area of ID/DD Nursing maintaining a level of excellence and expertise. The Registered Nurse Certification in Developmental Disabilities Nursing (CDDN) was initially developed in 1995 in collaboration with the National League for Nursing, and was updated in 2003 by Health Education Systems, Inc. (HESI). HESI has since been purchased by Elsevier Publishing and was updated again in 2008 by DDNA in collaboration with Elsevier. It is the only certification program for registered nurses specializing in the field of developmental disabilities (Developmental Disabilities Nurses Association, 2015).

### **Shared Decision Making**

Shared decision making (SDM) is a concept studied in the literature when a decision is being made for medical treatment options. However, the process has not been adequately studied in relation to the shared decision making for parents placing an adult child with ID/DD into a residential group home. This gap in the professional research literature formed the basis for this inquiry. The purpose of this Grounded Theory study was to generate a substantive

theory that describes and explains the decision-making process used by parents when they made the decision for residential group home placement for their adult child with ID/DD.

### **Definition of Terms**

Several terms need to be defined for the purpose of this study. These terms and acronyms are used in the chapters that follow as they are defined below:

1. *Family Caregivers*: Family caregiver is a spouse, adult child, other relative, partner or friend who has a personal relationship with, and provides a broad range of unpaid assistance for an older adult with a chronic or disabling condition (family caregiver = care partner, or care giving family) (Family Caregiver Alliance: National Center on Caregiving, 2013).
2. *Residential Placement*: A placement, usually arranged and paid for by a state agency or the parents, where an individual with special needs resides (OPWDD, 2013).
3. *Intellectually Disabled/Developmentally Disabled (ID/DD)*: The federal definition of the term *Intellectual Disability/Developmental Disability* means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairment. It is manifested before the individual attains age 18; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: a) self-care, b) receptive and expressive language, c) learning, d) mobility, e) self-direction, f) capacity for independent living, and g) economic self-sufficiency. ID/DD reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of

- assistance that are of lifelong or extended duration and are individually planned and coordinated (OPWDD, 2013).
4. *Parent Caregivers*: The parents will be the person actively involved in the decision process regarding residential group home placement of their adult child with ID/DD. Parent participants can be a biological parent, a step-parent, or an adoptive parent.
  5. *Decision*: Consent to the decision is a culmination of the information that was provided during the disclosure. It can be a formal consent that is signed by the patient (parent caregivers) authorizing agreement to proceed (Sugarman, 2003).
  6. *Shared Decision Making*: Effective decision making include best evidence and specific patient considerations, as well valuable information provided to the patient and family prior to the decision making, encompassing explanations about the patient's medical condition, and the benefits and risks of various treatment options (Godolphin, Towle, & McKendry, 2001).
  7. *Community Residential Settings*: Residential settings are licensed by OPWDD to provide housing and related services. These homes can be operated by OPWDD or nonprofit agencies. These settings can include supervised group living (a home with 24-hour staffing and supervision), semi-independent or supported group living (a home with less than 24-hour staffing and supervision) (OPWDD, 2015).
  8. *Family Care*: Family care is a licensed residential program that provides a family living experience through a structured and stable home environment, including the support, guidance, and companionship found within a family unit. Family care providers are homeowners who receive a monthly stipend to provide services within their homes (OPWDD, 2015).

9. *Non-Certified Housing Options*: Non-certified housing options include services that assist persons with ID/DD to locate, lease, or buy, and access residential arrangements which are alternatives to traditional congregate living situations. Among these types of living arrangements are shared or matched home sharing, independent living, HUD rental subsidies, and low-income home ownership programs (OPWDD, 2015).
10. *Intermediate Care Facility (ICF)*: As defined by NYS OPWDD, Intermediate Care Facilities (ICF) are designed for those individuals whose disabilities limit them from living independently. Services may be provided in an institution or a community setting. For the most part, ICFs support individuals who are unable to care for their own basic needs, and require heightened supervision and the structure, support, and resources that define this program type. ICFs provide 24-hour staffing supports for individuals with specific adaptive, medical, and/or behavioral needs and includes intensive clinical and direct care services, professional developed and supervised activities (day services), and a variety of therapies (e.g., physical occupational or speech) as required by the individual's needs (OPWDD, 2015).
11. *Individualized Residential Alternative (IRA)*: As defined by NYS OPWDD, an IRA is a type of community residence that provides room, board, and individualized service options. Supervised IRAs provide 24-hour staff support and supervision for up to 14 individuals. Day services are also available for individuals living in IRAs and may include day habilitation, prevocational services, and supported employment. Depending on the individual's skill level, some may be competitively employed. Those individuals residing in an IRA may apply for the Home and Community-Based

- Services (HCBS) waiver program. When in the program, the individual is assisted in selecting a service coordinator who will act on his/her behalf. A service coordinator can be chosen from any agency that is authorized to provide service coordination. It is the responsibility of the service coordinator to identify the services the individual needs or desires and to develop an Individualized Service Program (ISP) (OPWDD, 2013).
12. *Placement*: The change of moving from one location to another affects the well-being as well as has significant ramifications for all those involved in the process. These life-changing events comparably affect people with ID/DD as well as their families who must be supported during and after the process of placement (Alborz, 2003).
  13. *OPWDD*: The NYS OPWDD coordinates and provides services for people with developmental disabilities and conducts research into the causes and prevention of developmental disabilities. OPWDD provides access to services through a regional system dividing the New York State into DDSOs (OPWDD, 2015).
  14. *DDSO aka DDRO*: DDSO is an acronym for Developmental Disabilities Services Office aka Developmental Disabilities Regional Office. There are 13 DDSO/DDROs across New York State. Contacting the local DDSO/DDRO is a person's first step toward receiving the services he/she may want or need (OPWDD, 2015).
  15. *Child or Minor*: This term means a person who has not attained the age of 18 years (New York Department of Mental Hygiene, 2013).
  16. *"Substantial Handicap to a Person's Ability to Function Normally In Society"*: A "substantial handicap to a person's ability to function normally in society" exists when the person is prohibited from engaging in substantial aspects of self-care or

- self-direction independently and/or when the developments of self-care and self-direction skills are significantly below age level (OPWDD, 2015).
17. *Substantial Handicap Determination*: This determination is typically done by using a nationally normed, validated, comprehensive, individualized measure of adaptive behavior, which is administered by a qualified practitioner. A lower IQ does not automatically mean there is a substantial handicap (OPWDD, 2015).
18. *Medicaid Service Coordination*: This Medicaid State Plan service is provided by the OPWDD to assist persons with developmental disabilities in gaining access to necessary services and supports appropriate to the needs of the individual. MSC is provided by qualified service coordinators and uses a person-centered planning process in developing, implementing, and maintaining an Individualized Service Plan (ISP) with and for a person with developmental disabilities or mental retardation. MSC promotes choice, individualized services and supports, and consumer satisfaction. In order to receive MSC, a person must have a documented diagnosis of a developmental disability; be enrolled in Medicaid; demonstrate a need for ongoing and comprehensive, rather than incidental, service coordination; choose to receive MSC or have consent given on their behalf by an authorized individual; live outside of an Intermediate Care Facility (ICF), Developmental Center (DC), Psychiatric Hospital, Small Residential Unit (SRU), Nursing Facility or Hospital, or any other Medicaid-funded setting that provides service coordination; and not be enrolled in any other comprehensive Medicaid long-term service coordination program (OPWDD, 2015).

19. *Intelligence Quotient (IQ)*: The IQ test is an instrument measuring intellectual functioning, which refers to the mental ability for areas such as learning, reasoning, and problem solving. A test score between 50 and 70 indicates a limitation in intellectual functioning (Cheung, 2013).
20. *Legal Guardian*: When a child with a disability reaches the age of 18, he or she is legally considered to be an adult who can manage his/her own affairs. Parents or relatives who feel their child may not be able to manage his or her own affairs may consider applying to the Surrogate Court to become legal guardian. A legal guardian is responsible to ensure the individual's rights, interests, and desires are protected. A guardian's powers are similar to that of a parent over a child; however, the guardian does not assume any personal financial liability. A legal guardian will be able to make decisions about medical treatment, where a person will live, and what kind of care they will receive. A guardian is expected to know and understand the individual's wishes and desires and advocate for the individual, but not to limit them in achieving their fullest potential (Family Residences and Essential Enterprises, 2013).
21. *Incapacity or Incompetency*: The state of a person who is impaired by an intoxicant, by mental illness or deficiency, physical illness, or disability to the extent that personal decision-making is impossible; a person's inability to make and then act upon personal and/or property decisions on his or her own behalf (National Guardianship Association, 2013).
22. *Informed Consent*: A person's agreement to allow something to happen, made with knowledge of risks involved and the alternatives. A patient's knowing choice about a



- medical treatment or procedure, made after a physician or other healthcare provider discloses whatever information a reasonable prudent provider within the medical community would give to a patient regarding the risks involved in the proposed treatment or procedure (Garner, 2009).
23. *Direct Services*: These services include medical and nursing care, care/case management and case coordination, speech therapy, occupational therapy, physical therapy, psychological therapy, counseling, residential services, legal representation, job training, and other similar services (National Guardianship Association, 2013).
24. *Disabled Person*: A person 18 years of age or older deemed by the court to be lacking sufficient understanding or capacity to make or communicate responsible decisions concerning the care of his person or financial affairs (National Guardianship Association, 2013).
25. *Capacity*: Legal qualification, competency, power, or fitness; ability to understand the nature of the effects of one's acts (Garner, 2009).
26. *Power of Attorney*: A written document in which one person (the principal) appoints another person to act as an agent on his or her behalf, thus conferring authority on the agent to perform certain acts or functions on behalf of the principal (OPWDD, 2015).
27. *Medical or Durable Power of Attorney*: This allows a specified person to make medical decisions in cases of mental or physical incapacitation. In cases where an individual is deemed unfit or incapable of making health or financial decisions, the court may assign guardianship or power of attorney. When authorizing power of attorney responsibilities, individuals may specify instructions for different situations

or limit power of attorney rights. The person must be deemed “of sound mind” to create a power of attorney (OPWDD, 2015).

28. *Office for People With Developmental Disabilities (OPWDD)*: The OPWDD Mission Statement is “We help people with developmental disabilities live richer lives.” The OPWDD Vision Statement is: “People with developmental disabilities enjoy meaningful relationships with friends, family, and others in their lives, experience personal health and growth and live in the home of their choice, and fully participate in their communities.” OPWDD Values are:

Describe how we as employees of OPWDD interact with the individuals we serve, families, staff, the community and each other:

Compassion - The capacity to appreciate what others think and feel.

Dignity - The recognition of the worth of each person and the treatment of individual rights and preferences with respect, honor, and fairness.

Diversity - The celebration, respect, and embracing of the differences among us because these differences strengthen and define us.

Excellence - The continual emphasis on innovation, increasing knowledge, and delivering the highest quality supports and services.

Honesty - The foundation on which trust is built and truth is communicated.

The Guiding Principles that frame how OPWDD conducts its business are: “Put the person first - People with developmental disabilities are at the heart of everything we do, and this person-first ethic is embodied in the way we express ourselves, and in the way we conduct our business.”

Maximize opportunities – OPWDD’s vision of productive and fulfilling lives for people with developmental disabilities is achieved by creating opportunities and supporting people in ways that allow for as many as possible to access the supports and services they want and need.

Promote and reward excellence - Quality and excellence are highly valued aspects of our services. Competency is a baseline. We find ways to encourage quality, and create ways to recognize and incentivize excellence to improve outcomes throughout our system.

Provide equity of access - Access to supports and services is fair and equitable; a range of options is available in local communities to ensure this access, regardless of where in NYS one resides.

Nurture partnerships and collaborations - Meaningful participation by people with developmental disabilities strengthens us. OPWDD staff and stakeholders create mechanisms to foster this participation. The diverse needs of people with developmental disabilities are best met in collaboration with the many local and statewide entities who are partners in planning for and meeting these needs, such as people who have developmental disabilities, families, not-for-profit providers, communities, local government and social, health, and educational systems.

Require accountability and responsibility - There is a shared accountability and responsibility among and by all stakeholders, including individuals with disabilities, their families, and the public and private sector. OPWDD and all its staff and providers are held to a high degree of accountability in how they

carry out their responsibilities. We strive to earn and keep the individual trust of people with developmental disabilities and their families, as well as the public trust. Creating a system of supports that honors the individual's right to be responsible for their own life and accountable for their own decisions is of paramount importance (OPWDD, 2013).

### **Summary**

It is important to study how parent caregivers make the decision for residential group home placement of their adult child with ID/DD. While the usual focus of the medical community, physicians, nurses, social workers, and mental health professionals is understandably on the adult child with ID/DD, little attention has been given in the literature to how the disability affects the parents. More specifically, this phenomenon represents a unique gap in nursing literature and nursing knowledge of how the disability affects parents when they need to make the decision for possible residential group home placement of their adult child with ID/DD. Individuals with ID/DD are often not able to express concerns or make decisions about their placement. Therefore, decision making about their child's future living arrangements is delegated to the parent caregivers. With a more comprehensive understanding of the parents' feelings and concerns, healthcare professionals can gain greater insight into a caregiver's decision.

The results of this study and the information gained will make a valuable contribution to better understanding and helping parents of all children with ID/DD in their decision-making process for residential group home placement. Greater understanding and clarity of this phenomenon will inform clinicians, nurses, and members of the interdisciplinary healthcare team about the creation of targeted interventions or strategies for this unique, vulnerable population.

These targeted interventions and strategies can potentially influence parent decision-making experiences positively, improve their decision-making abilities, and offer professionals direction for further research.

## **Chapter 2: REVIEW OF THE LITERATURE**

### **Introduction**

This chapter reviews the literature related to caring for a person with ID/DD and decision making. It is organized into sections that address: a) caregiving; b) placement concerns; c) transition planning; d) quality residential care; e) family stressor: future planning; f) long-term care decision making; g) hospice placement; h) ID/DD institutional placement; i) skilled nursing facility placement; and j) long-term respite care for adults with ID/DD. It discusses decision-making models and outlines a concept analysis on decision making for residential group home placement. It summarizes the related literature that guided the development of the research question and processes to capture how parents of adult children with ID/DD make decisions about residential group home placement.

Parents of adult children with ID/DD have special and unique needs. They often worry who will fill their caregiver and advocate role when they are no longer able to do so. The need for future planning is elevated in importance due to the increase life expectancy of people with ID/DD. Advancement in medical care, early diagnosis and intervention, and technology increase the life expectancy of those with ID/DD. The average lifespan of a person in the United States with ID/DD is now approaching 70 years (Janicki, Dalton, Henderson, & Davidson, 1999). In a study that investigated the Down syndrome population by Bittles, Bower, Hussain, and Glasson (2007), it was reported that community inclusion, early access to services, and clinical intervention have resulted in an increase in the lifespan of people with DS. Life expectancy in 1940 for people with DS was 12 years of age, as compared to life expectancy of 60 years of age as reported in 2006. As of 2007, it was estimated that more than one half of adults with ID/DD

live with a family member, in most situations a parent. Many parents are having children later in life, resulting in an increased age of parent caregivers (Prouty, Alba, & Lakin, 2008).

It has been this researcher's experience that parents of children with ID/DD report experiencing feelings of guilt with the birth of a child with a disability, and are living with chronic sadness and sorrow. Parents sometimes mourn the loss of the "perfect child" they envisioned parenting and raising.

How parents make the decision about residential group home placement for the adult child with ID/DD represents a significant gap in the literature. Aging parents caring for their adult daughters and sons with ID/DD are under constant duress due to a lifetime of caring. They may have health concerns and financial problems, may be caring on their own due to the death of a spouse, have constant worry about the future of their adult child with ID/DD, and are possibly uncomfortable approaching healthcare professionals for help. Professionals, including nurses who work with these parents, must take these concerns into consideration when planning interventions to assist parents (Dillenburger & McKerr, 2009) and when offering support and guidance through the decision-making process.

Parents can obtain and receive information on the various types of services and supports that are available. This information can help them apply the knowledge they receive. The information and support from the healthcare team, particularly nurses, can help increase a parent caregiver's ability to advocate, increase confidence in their parenting, and assist with navigation through the OPWDD system. The decision regarding possible placement of the adult child with ID/DD into a residential group home can only be considered when the parents are "ready."

## **Review of the Literature**

### **Caregiving**

Caring for a child with ID/DD is a tremendous responsibility for the parents and family. Many of these children require constant supervision into their adult years and beyond. A significant number of children with developmental disorders will also experience intellectual deficits, sensory and communicative disorders, and have substantial limitations in self-care (Raina, O'Donnell, Rosenbaum, & Brehaut, 2005). Parents caring for adult children with disabilities was investigated in a study by Dillenburger and McKerr (2009). The research reported the lack of future planning for the child with disabilities as one of the key issues. In the literature, much of the research focuses on the caregiver caring for persons who are acutely ill, or the very elderly and the physical, social, financial and emotional effects on the caregiver's life. For the caregiver of the adult child with ID/DD, the physical and psychological demands on the family continue even after the placement decision. Research on children with Down syndrome has shown that parents who care for children with Down syndrome with ID/DD experience impaired physical functioning (Hedov, Anneren, & Wikblad, 2000). In a study of caring for the spouse as the impairment increases both physiologically and neurologically, caregivers reported increased health risk behaviors, poorer health perception, and an increase in depression and anxiety (Beach, Schulz, Yee, & Jackson, 2000). In a study that examined spouses caring for an elderly individual with disability, it was determined that caregivers who experience emotional duress and mental strain were identified to be at a greater risk for mortality when compared to non-caregivers (Schulz & Beach, 1999).

In a study on Down syndrome, it was found that individuals with ID/DD often have difficulty learning self-care skills. If they possess the cognitive and motor ability to learn these



tasks, the learning of the completion of self-care skills occurs at a much slower rate than those without ID/DD. Some individuals will never be independent in activities of daily living. This lack of the ability to be independent can result in the primary caregiver experiencing strain resulting from having to fully assist with bathing, dressing, eating, toileting, and other activities of daily living (Carr, 1975).

### **Unique Placement Concerns for Adults With Down Syndrome**

The lifespan for adults with Down syndrome (DS) has increased exponentially with early access to services, inclusion in the community, and clinical intervention. In their study, Patti, Amble, and Flory (2010) found that adults with DS experience more residential relocations than adults with ID/DD without DS. The causative factors are the higher incidence of dementia associated with DS, as well as functional decline that occurs with aging. Older adults with ID/DD without DS are more likely to remain in the residential group home placement than those with DS. When an individual with DS exhibits decline in functioning requiring increased support and care, he or she may need transfer to a facility such as a nursing home that can provide a greater level of care (Patti, Amble, & Flory, 2010).

The interdisciplinary team, and particularly nurses, need to work with parents seeking residential placement for their adult child with DS, and address the needs of those aging with DS to enable transition to a residential group home. This preparation and continued support is paramount to their being able to remain in a residential group home setting for as long as possible. The continued support provided by nurses and the healthcare team may assist parents in a future second placement decision when the group home is no longer able to safely support the individual in the residential setting, and alternative placement with greater supervision and medical oversight is warranted.

## **Transition Planning**

Although current efforts to support parents of children with ID/DD are for them to remain in the family home setting, educational system services are available from the state education department for the child with ID/DD until the end of the school year when the student is age 21. At this time that OPWDD becomes responsible for the person with ID/DD adult services. It has been this researcher's experience that transition planning should begin early in the child's life. Parents have questions about what supports are available when school ends and life as an adult begins for their adult child with ID/DD. There will continue to be a need for out-of-home residential group home placement for individuals with ID/DD. The assumption is individuals who have more complex medical needs, severe ID/DD, and elevated behavioral problems are placed in community residences at increased proportions (Lakin, Hill, & Bruininks, 1988). Bromley and Blacher (1991) explored why children with severe ID/DD were placed outside of the home. They identified three factors associated with residential placement including the individual characteristics of the child with ID/DD, such as: a) the level of ID/DD and behavioral challenges; b) family characteristics including family size, marital status, parent caregiver health, daily stress; and c) lack of support services such as babysitting and respite services. Although Bromley and Blacher (1991) investigated "why" the decision was made for residential placement outside the family home, missing in the research literature is "how" the decision was made for residential placement outside the home for the adult with ID/DD.

## **Quality Residential Care**

Future planning for a child with ID/DD is a growing concern for parent caregivers. Several factors surrounding the provision of quality care have been identified in the literature. McDonald, Owen, and McDonald (1993) explained that a quality residential group home

requires a formal transition beginning early in the life of the child with ID/DD. Parents and the child with ID/DD need to be included in this transition process well before there is an actual change in the residential setting for the individual. Quality residential care includes family involvement and continued support of the family. In addition, staff working in the group home need to be prepared to be working with individuals with increased behavior problems. Finally, the staff working in the residential home require adequate training to support individuals with ID/DD to learn skills that will enable them to be as independent as possible.

### **Family Stressor: Future Planning**

A study done by Hewitt et al. (2010) explained that families of children with ID/DD generally favor a lifetime assistance model. They identified that one stressor of parents with adult children with ID/DD is planning for the future of their child. Most importantly in that study, parents were concerned about the transfer of care when the parent caregivers are no longer able to care for their adult child.

Hewitt et al. provided ideas about the significance of future planning for individuals with ID/DD and the specific areas that may be most beneficial to the families. These areas include early planning for the quality of life and financial well-being for the person with ID/DD. The findings are useful to the healthcare team, including nurses who are positioned to help families in future planning and decision making.

### **Shared Decision Making**

Multiple concepts have been used synonymously in the literature to describe the process of shared decision making: informed, decision, competent, shared, partnership, shared decision, and collaboration. Although these concepts are inclusive of the elements of both process and outcome, the concept of shared decision making encompasses all the elements necessary to make

a decision. Information and sharing of information are the precursors to a decision and may assist parents in the decision-making process. Some models pertain to other types of decision making, such as the patient/physician and treatment choices. However, these models offer insight into the parents making decisions about residential group home placement for their adult child with ID/DD. The models are described as follows.

A model that helps bring patients (parents) into the decision-making process is shared decision making (SDM). Effective decision making includes the best evidence and specific patient considerations, as well as valuable information provided to the patient and family prior to the decision making. The utilization of effective decision making encompasses explanations about the patient's medical condition as well as the benefits and risks of various treatment options (Godolphin et al., 2001). In a dynamic healthcare environment with a cost containment focus, nurses are faced with many challenges. Changing from a paternalistic approach to one of partnership denotes sharing between partners to achieve desired outcomes (Hain & Sandy, 2013). The patient-provider partnership continues to evolve from the traditional paternalistic model in which the provider dictates the treatment plan to a partnership model in which the patient's autonomy and preferences are valued and respected. This process involves the provider and patient at a minimum, and it will often include multiple members of the healthcare team, as well as the patient's family members or the legal healthcare surrogate for those who are impaired (Hook, 2006). It was the opinion of the researchers that fostering an environment of shared collaboration as partners in care can be an effective approach to empower patients to engage in their healthcare and ultimately improve health outcomes (Hain & Sandy, 2013).

Charles et al. (1997) outlined four key characteristics that are necessary in order to classify a physician-patient decision-making interaction as SDM. The authors outlined the following characteristics:

1. SDM involves at least two participants—the physician and patient.
2. Both parties (physicians and patients) take steps to participate in the process of treatment decision making.
3. Information sharing is a prerequisite to shared decision making.
4. A treatment decision is made and both parties agree to the decision.

The first characteristic includes a clinician and a patient making the decision together. The second characteristic recognizes that some patients may not want to participate in the decision-making process simply due to lack of motivation to be involved in the process, or they may lack the cognitive ability to make the decision and would prefer the physician to make the decision. Other individuals may state their preference not to participate, or in the case of the patient with ID/DD, they may actually lack the ability to participate. In this circumstance, a decision aid (resource material) could provide information to the parents encouraging a more active role in the decision-making process. The third characteristic requires the physician to provide information to the patient regarding treatments, treatment alternatives, risks, and benefits. The patient can also bring information to the meeting. Many patients use the internet to gather information (Elwyn, Edwards, & Kinnersley, 1999) and bring it to the encounter. Information and values are brought to the encounter by the patients and the physician. The fourth characteristic of SDM is that both parties involved in the process agree on the decided treatment option. Those involved in the process endorse the treatment to implement, not

necessarily in agreement or convinced that this is the best treatment option. It is a mutual understanding where those involved share responsibility for the choice made.

There is no one path to SDM and the characteristics outlined can be accomplished by a variety of actions (Charles et al., 1997). In the situation where the person with ID/DD is unable or unwilling to participate in the shared decision making, the “patient” would be replaced with the parents in the characteristics of the process outlined. By doing so, this will provide for SDM to be applicable to this unique population and phenomenon being studied. It will attempt to identify the degree of SDM among clinicians, interdisciplinary health care team, and parent caregivers in this vulnerable population during the decision making.

Towle and Godolphin (2006) described SDM as those types of decisions that the patient and physician share. These not only include risks and benefits but more specifically the patient’s own values and characteristics. The SDM process is a collaborative process between clinicians and patients. The goal is to develop a treatment plan that corresponds to the clinician’s role to help the patient to reach health-directed goals, while at the same time considering the patient’s preference on how it will be accomplished (Charles et al., 1997). In the shared decision-making process, both the patient and the professional bring their preferences and factual information to the decision process and jointly consider the information together in order to reach a shared decision (Sandman & Munthe, 2010). Parents may benefit from proactive and systematic SDM, and support for potential future residential placement of their adult child with ID/DD.

The literature contains numerous studies and information on utilization of the shared decision-making model for medical treatment option. Shared decision making has been and continues to be utilized in many areas of healthcare. Some examples of the utilization of the SDM process include decisions regarding the end of life care (Frank, 2009), in primary care

(Elwyn et al., 1999), in complementary and alternative medicine (Sugarman, 2003), as well as in various treatment decisions (Falzer & Garman, 2009). The literature also includes research on placement in nursing homes or assisted living facilities for the general population (Lundh, Sandberg, & Nolan, 2000; Pastor & Vogel, 2011), but absent from the literature is research on placement of the individual with ID/DD in a residential group home. A significant gap exists in the literature studying the shared decision-making process for parents on how they made the decision about residential group home placement for their adult child with ID/DD; as well, the nurse's role in the decision process has not been studied.

One of the challenges of the population with ID/DD who have limited cognitive ability is that throughout their lives, decisions about their welfare, and particularly their healthcare, are often made by parents' consent. The partnership between physician and patient is fostered by patients who have developed more "consumerist trends" yielding a sense of entitlement, desire, and demand for information disclosure, as well as the readily available access on types of treatments and modalities (Elwyn et al., 1999). Historically, physicians were taught to be paternalistic when caring for their patients. In the past, physicians were trained to withhold information from patients. The approach failed to accept the patient as an equal partner. Physicians are being taught to work toward accepting the patient as a partner, and are developing the necessary skills to involve their patients as partners in care (Moulton & King, 2010; Weston, 2001). Nurses and other members of the interdisciplinary team have an integral role in supporting persons with ID/DD and their families in the decision-making process.

### **Models of Decision Making**

Several types of decision-making models are discussed in the literature. In addition, it is important to understand that there are many different types of decision-making contexts.

Decisions are made about long-term care, emergency decisions, palliative care, cancer care, treatment options, and the list where decisions are needed could be endless. It is necessary to consider that different models of decision making may be more or less appropriate, or possible in varying contexts. The following models describe the patient and the professional. These models have applicability to this research. Studies about physicians or professionals and patients may have relevance to the nurse, healthcare team, and the parent of the adult child with ID/DD.

Leading among these are the Shared Rational Deliberative Patient Choice, Shared Rational Deliberative Paternalism, Shared Rational Deliberative Joint Decision, and Professionally Driven Best Interest Compromise Models (Sandman & Munthe, 2010). The authors Sandman and Munthe (2010) described these models as high-level dynamics of the SDM process. Inclusion of high-level dynamics represents the optimal decision process and reaching the decision that exemplifies and satisfies both paternalism and patient choice. Reaching a decision that is inclusive of consideration and adaptation of the professional and patient's beliefs, ideals, and values represents the ideal decision process.

### **Shared Rational Deliberative Patient Choice Model**

In the decision-making model of Shared Rational Deliberative Patient Choice, the professional and the patient have discussion. They participate in conversation considering all the options as well as facts and preferences. With this model, ultimately it is the patient who decides on what option to select (Sandman & Munthe, 2010).

### **Shared Rational Deliberative Paternalism Model**

In the decision-making model of Shared Rational Deliberative Paternalism, the patient and the professional have a discussion. They participate in conversation considering all the options as well as facts and preferences. However, although there was dialogue between the two



parties, ultimately it is the professional who makes the decision about what option to select (Sandman & Munthe, 2010).

### **Shared Rational Deliberative Joint Decision Model**

Sandman and Munthe (2010) described this model as exemplifying communicative action:

Communicative action aims at consensus between parties, not necessarily in line with the predetermined goals or interests of any parties. In order to achieve this the discourse should be surrounded with a number of constraints, which to a large extent are applicable on the Shared Rational Deliberative Joint decision Model: 1) All parties concerned by the decision should be given the opportunity to take part . . . . 2) All the parties should be able to express whatever they find as relevant needs, interests, suggestions, reasons etc. . . . 3) All parties should be open to seriously consider the interest of the other party and allow their own interests to be radically questioned. . . . 4) No goal or interest should be given more weight due to the position of the party. . . . 5) All interests, goals and reasons should be openly displayed, there should be no hidden agenda. . . . (p. 78)

### **Professionally Driven Best Interest Compromise Model**

In the Professionally Driven Best Interest Compromise Model, Sandman and Munthe (2010) described the emphasis as being on patient autonomy and respect for the patient. When the professional is acting in a strategic manner, the patient needs to be aware of and able to relate to the action. The professional must respect and consider patient autonomy to the fullest extent. In the decision making, the professional must care for the patient's autonomy as completely as possible by achieving optimal decision-making, while at the same time carefully depicting the decisional situation to achieve what is necessary to achieve.

### **Informed Shared Decision Making**

Informed Shared Decision Making (ISDM) can be defined as those decisions made from best evidence, including risks and benefits. The components of ISDM include discussion of risks and benefits and, in addition, consideration of the patient's preferences. The ISDM takes place in a partnership with the physician and the patient. The patient is therefore equally responsible

to bring a certain level of ability to the encounter (Towle & Godolphin, 1999). In a study conducted by Towle, Godolphin, Grams, and LaMarre (2006) based on a review of the literature, a model was developed that included a list of eight competencies of what the physician should bring to the informed shared decision-making model. Towle and colleagues noted that informed shared decision making rarely occurs, despite the fact that the concept of patient involvement in decisions about their healthcare is the focus of a great deal of academic activity. The competencies for informed shared decision making as described by Towle and colleagues are the following:

1. Partnership: Develop a partnership with the patient.
2. Information: Establish or review the patient's preferences for information (such as amount or format).
3. Role: Establish or review the patient's preferences for role in decision making (such as risk taking and degree of involvement of self and others), and the existence and nature of any uncertainty about the course of action to take.
4. Ideas: Ascertain and respond to patient's ideas, concerns and expectations (such as disease management options).
5. Choices: Identify choices (including ideas and information a patient may have) and evaluate the research evidence in relation to the individual patient.
6. Evidence: Present (or direct patient to) evidence taking into account 2 and 3 above, framing effects (how presentation of the information may influence decision-making), etc. Help patient to reflect upon and assess the impact alternative decisions have with regard to his or her values and lifestyles.
7. Decision: Make or negotiate a decision in partnership and resolve conflict.

8. Plan: Agree upon an action plan and complete arrangements for follow-up. (Towle et al., 2006)

### **Informed Decision Making: Consent**

In today's healthcare systems, patients are required to be completely involved in making decisions about their healthcare due to the ethical and legal trends in relation to patient rights, informed consent, and patient autonomy. The American Medical Association recognizes that the patient right to make a decision can be effectively exercised only if the patient possesses enough information to make an informed choice, and that the patient should make his or her own determination about treatment (Moulton & King, 2010). Physicians are required by the American Medical Association to disclose all relevant medical information to patients enabling them to make decisions based upon their life goals, values, and beliefs. Therefore, physicians and nurses are expected to acknowledge and respect a patient's decision even if it does not align with the physician's or the advanced practice registered nurse's medical judgment, or promote physical health for the patient (Moulton & King, 2010). This is complex in situations that include competence and emotional choice that is inherent in placement decisions for adults. Adult children with ID/DD may or may not be cognitively capable of fully participating in such decisions and depend upon parents to act on their behalf.

**Informed consent.** Throughout the life of persons with ID/DD who are lacking cognitive ability, decisions are made on their behalf. Therefore, understanding of the informed consent process is relevant to this investigation. Parent caregivers often experience the necessity to make decisions in all aspects of their child's life. Throughout the life of their child, parent caregivers are faced with a barrage of decisions including treatment decisions such as possible surgical procedures requiring informed consent. The processes utilized to make decisions

throughout the lifetime of a child with ID/DD can contribute to and impact the parents' placement decision process.

In 2004, Whitney, McGuire, and McCullough defined informed consent as that which is always expressed, meaning intervention is explicitly authorized by the patient; in simple consent the patient's agreement is assumed and the physician does not discuss risk or alternative treatments. Within the United States, with the exception of those states where a statute determines otherwise, informed consent needs to be obtained only when a particular intervention, or lack of the intervention, presents a substantial risk for harm. If risk is great, the physician will require a patient to grant permission for a treatment, or non-treatment, prior to implementation of the treatment or procedure. If the risk is minimal and the patient agrees to the prescribed treatment, the patient agreeing or not agreeing to the outlined plan of care is demonstrated by following through with the physician's instructions for treatment. Therefore, a simple consent is appropriate and ethically acceptable for low-risk decisions.

Conversely, informed consent would be appropriate for high-risk decisions. During the informed consent process, the patient and the physician should engage in a thorough informed consent process (Whitney et al., 2004). Beauchamp and Childress (1994) discussed that informed consent should be a process rather than just the signing of an informed consent form by a patient. Their model involves three steps including threshold, information, and consent. In the first step of threshold, the person should have the ability to make a voluntary choice, the capacity for adequate decision making, and competency to provide informed consent (Sugarman, 2003). In the second step is the information: during this step the patient should be given information in terms and descriptions that are understandable about the risks, benefits, and alternatives. The third step of consent is after the patient has had the opportunity to ask questions and decipher and

consider the information that was provided to them. A consent document is a culmination of the information that was provided during the disclosure and is then signed by the patient authorizing agreement to proceed (Sugarman, 2003).

In addition to being spoken to, patients should be supplied with detailed written handouts and brochures they can read at their leisure, and have time to review and call back the physician to ask questions. Being told about a potential serious side effect or consequences of a treatment or decision or reading about it in a pamphlet conveys a very different message than just hearing it from the physician during a consultation (Brody, 2007). In the circumstance where the person with ID/DD is unable to sign consent, the parent would be the representative for the patient. Parents considering placement are often given written educational and informational material in the form of handouts and brochures. Parents eventually need to sign a variety of consents for placement to occur.

### **Long-Term Care Decision Making**

Long-term care decision making by children for adult parents such as elder care, end of life care, skilled nursing facility placement, and hospice placement is a reverse parallel to this research study that addresses parents making decision placement for their adult child with ID/DD. Although they are different, many of the experiences of the decision maker have similarities and can serve as a blueprint regarding the decision-making process.

**Hospice placement.** In their study, Casarett, Crowley, Stevenson, Xie, and Teno (2005) investigated the placement of a family member into hospice services. Hospice care is often identified as end of life care. In most cases, insurance policies require that families agree to surrender the use of aggressive life-sustaining treatment. These families are faced with complex considerations as often the decision for hospice placement occurs when the loved one is near the

end of life, requiring this consideration to be made in a short period of time. The need for information regarding treatment, medications, and services is tremendous. The families are most likely already experiencing caregiver challenges and burdens during this complex enrollment decision-making process. During this study, it was identified that the need for information for the families was significant. It is important for members of the healthcare team to identify early the common priorities for information. This could dramatically assist the families with the hospice decision-making process.

**ID/DD institutional placement.** Although the current movement is toward community-based services, in the past the placement options for families were often limited, and institutionalization was sometimes their only viable choice. Identified in the literature was a study that explored families' past experiences seeking alternative out-of-home placement for their relatives into an institutional facility, as well as the deinstitutionalization resettlement experience into other community options (Mirfin-Veitch, Bray, & Ross, 2003). However, absent in the literature was research of the Shared Decision Making (SDM) process for placement of this special ID/DD population from the family home to placement into a residential group home setting. The study by Mirin-Veitch et al. focused on families, as many of the parents of these adults with ID/DD were already deceased. The researchers also recognized that entire families are affected by major changes in delivery services for their loved one. Results of the study were:

- a) families knew that at some point placement would be necessary for their loved one;
- b) identification that the lack of support created a strain on the caregiver;
- c) difficulty in balancing things;
- d) work, family, and altered family life, and their loved one with ID/DD;
- e) influence from the healthcare team advising the family to seek outside help for their loved one with ID/DD;
- f) giving "permission"; and
- g) consideration of the siblings of the person with

ID/DD. All of these factors were identified precipitants to decision making regarding placement into the institutional setting.

**Skilled nursing facility placement.** There is some related evidence present in the literature of the experiences of spouses facing the decision-making process of placing a partner in a care home for older people. Lundh et al. (2000) conducted a study in Sweden and their results showed a significant lack of planning for the person's entrance into the care home (a generic term for accommodation including nursing homes) and domination by the healthcare professional team at this point of the process. The study also revealed the emotional response of ambivalence that the spouses experienced in relation to the move, as well as the problems in developing and maintaining relationships with the staff in the care home (nursing home). In the study, several of the spouses reported that they had reached the decision for placement in almost complete isolation. The researchers identified the area neglected is the support that is needed before, during, and after placement in a care home (Lundh et al., 2000). Although the study is 15 years old, the lack of support identified in this study, as well as the possibility of reaching the decision in complete isolation, could be applied to the context of the parents facing the decision about residential group home placement for their adult child with ID/DD.

Placement of an older adult into a long-term care facility is a difficult life experience. The decision is often riddled with feelings of guilt and failure. It is just one of the many challenges of being a caregiver. There is a relinquishing of the significant emotional bond between the caregiver and the family member receiving care. A Grounded Theory study by Penrod and Dellasega (1998) explored the experiences of adults actively involved in the process of placing an older adult into a long-term care facility. It was determined that the decision process does not end abruptly when a person is placed, but rather the caregiver's role and

decisions are now changed to a home-based decision maker of the nursing home-placed family member. The study determined the lack of a supportive role and knowledge sharing of health care professionals during the decision-making process. There is an identified need for proactive caregiver education on decision-making process, care, and placement options.

Kellet (1999) examined family transition before, during, and following admission of an older relative in to a nursing home. Family members reported a sense of loss of control in that they felt as though they were not being heard, were being excluded and disempowered, experienced a sense of failure, and had the need to make a forced choice.

Wang (2011) explored the fundamental element of Chinese society of filial piety that is an attitude and a structure of Chinese society. Filial piety means that it is expected that adult Chinese children care for aging older parents. It is believed that placing an aging parent in a nursing home is immoral and unfilial. At this time, the roles, responsibilities, and family structures of adult children are changing and resulting in nursing home placement in some family situations. When assisting families that have decided on nursing home placement, it is important for healthcare professionals to understand their cultural beliefs and the pressures it places on families to keep the aging parent home with them.

**Long-term respite care for adults with ID/DD.** The purpose of respite services for those with ID/DD is to provide relief for parent caregivers on a short-term basis. However, in many situations it has unintentionally become long-term residential placement for individuals with ID/DD. There are many reasons why persons remain in respite care for a long period of time. The stress associated with caring for a person with ID/DD has been well documented in the literature, thus resulting in a growing demand for respite services. It has been determined that the current availability of respite accommodations cannot meet the demands of those who



are eligible for the services. Parents who make the decision for the use of respite services often have an adult child who is demonstrating challenging behaviors, has an increased level of care, possesses a severe disability, and exhibits communication difficulties. Increased use of respite services by single parents was also identified. Once they made the decision for the use of respite services, the parent often relied upon the placement accommodation on a long-term basis (Chan, Sigafoos, Watego, & Potter, 2001).

### **Concept Analysis: Decision Making for Residential Group Home Placement**

The researcher completed a concept analysis to explore the underlying structure of decision making for residential group home placement for persons with ID/DD, beginning with a detailed analysis of the concept of shared decision making (SDM) that provided the framework guiding this study. Although there is often controversy about using a conceptual model in a qualitative investigation, this concept analysis helped define the foundation of decision making. From the literature on SDM in medical treatment situations, the underlying definitions can be specified, and the ability to extrapolate the antecedents, critical attributes, consequences, and empirical referents of the concept of SDM as it applies to residential group home placement can be provided. See Appendix J for a hypothetical exemplar concept analysis that specifies SDM for parents of a person with ID/DD as a preliminary exercise that may supplement the findings of this qualitative inquiry. This concept map and case examples have been developed prior to the study in order to supplement the analysis and guide the questions. It can serve as a bridge from the conceptual underpinnings of SDM, the general literature on decision making and SDM, and the development of a methodological plan to elicit unique substantive elements of a beginning theory of parent decision making for residential group home placement of adult children with ID/DD.

It is important to clarify some terminology referring to Shared Decision Making (SDM) in this study on how parents make the decision for residential group home placement for their adult child with ID/DD. For the purpose of this study when discussing the “Patient,” it is referring to the parents; the “Physician” refers to the interdisciplinary healthcare team, particularly the registered nurse. Although the physician is involved in many aspects of the individuals’ medical care, the other members of the healthcare team predominantly address placement decision with parents in the process.

### **Summary**

The decision for placement of a family member into another living arrangement that will provide care was described in the literature as a process. The emotional needs of the decision makers and the family need to be recognized and supported. Often the emotional and psychological demands of caring are underestimated as compared to the physical burden of care.

Residential group home placement decision is a unique decision-making process; however, many similarities are shared with other placement decisions. Most congruent in similarities are those of the reverse parallel decision process of children placing adult aging parents into long-term placement settings.

Many of the decision-making experiences for alternative care are similar to the decision-making experiences of the parents of adult children with ID/DD. However, none of the available research clearly delineates how parents make the decision about residential group home placement for their adult child with ID/DD. Although some of the literature is dated and limited regarding the reverse (children placing parent into settings outside the home), the personal human experience regarding the decision transcends the passage of time.

The parent's responsibility of the adult child with ID/DD becomes more problematic as the parents themselves have health disabilities and chronic conditions, in many situations needing assistance themselves. A number of other studies have examined "why" a decision for alternative placement was made; however, representing a significant gap in the literature is "how" parents made the decision for residential group home placement for their adult child with ID/DD. Exploration has not been conducted from the point of view of parents of adult children with ID/DD and the issues they encounter with placement decisions. The parent caregivers of a child with ID/DD face lifelong challenges. At some point of time during the child's lifetime, the parents may need to consider a safe alternative, and the decision about residential group home placement of the adult child can be the result of numerous factors. Adequate examination of the factors occurring before, during, and after the placement decision, and the need for understanding how the placement decision process was achieved will provide necessary information and possible interventions for the healthcare team. This information will be specifically crucial for nurses to support the parents during the residential group home placement decision process.

To address these gaps in the research literature, this Grounded Theory study investigated the decision-making process used by the parents of an adult child with ID/DD as they made the decision regarding residential group home placement for their adult child.

## **Chapter 3: RESEARCH DESIGN AND METHODS**

### **Research Question and Purpose of the Study**

This researcher investigated the phenomenon of how parents make the decision for residential group home placement for their adult child with ID/DD. The purpose of this qualitative inquiry was to describe and explain how the parent caregivers of the adult child with ID/DD made the decision for placement. In addition, the researcher explored the decision process in an attempt to identify the presence of shared decision making among clinicians, nurses, the interdisciplinary healthcare team, and parent caregivers in this vulnerable population, which has been limited in the literature. Findings will inform professionals and caregivers on issues facing parents of persons with ID/DD at these critical developmental events.

### **Overview of Data Collection and Analytic Framework: Grounded Theory**

This qualitative study used the method of Grounded Theory. Qualitative research allows the researcher to get at the inner experiences, and the emic experience of the parent caregivers actively involved in the decision of placing their adult child with ID/DD in a residential group home (Strauss & Corbin, 1990). In addition, in order to enable the researcher to fully understand the phenomenon under study, the experience of a parent who has decided against residential group home placement was explored through interview. How a person makes meaning of what is happening to them can be discovered through the qualitative research process. Although generalization to a larger population is limited, qualitative investigation gives a deep explanation to illustrate a phenomenon and allows for rich in-depth description of the phenomenon. Grounded Theory generates a theory that accounts for a pattern of behavior that is relevant and problematic for those involved (Glaser, 1978). The basic building blocks for Grounded Theory

are the concepts grounded in the data. Grounded Theory is an action/interactional-oriented method of inductive theory building that describes and explains the behavior or system under study, and therefore is a methodology for developing theory. The main feature of Grounded Theory is the method of constant comparative analysis with the data collection and analysis occurring concurrently (Glaser & Strauss, 1967). Theory is developed through constant comparative analysis of the interview data. The insights gained from the process of constant comparative analysis are what inform the development of the theory. Each interview is compared and contrasted with all those that came before it prior to proceeding to the next interview. Grounded Theory identifies the basic social psychological problem, the core concept of an identified group, and the basic social psychological process used to resolve it (Glaser & Strauss, 1967).

### **Methodology in Grounded Theory**

With the Grounded Theory methodology, theory development is grounded in data that are systematically gathered and analyzed (Strauss & Corbin, 1994). The Grounded Theory methodology utilized for this study is predominately a Glaserian and Straussian Grounded Theory. Glaserian Grounded Theory was the original from which other variations have developed. Utilizing the Glaserian and Straussian approach, the research question aimed to discover problems the participants identified and find out how they managed solutions to those problems. Data were built from the phenomena of the study and explained the processes occurring within the phenomena. Theory was inductively developed using constant comparative analysis with data collection and analysis occurring concurrently. Sample size was determined when no new themes emerged from the data and saturation was reached. Sampling was purposive, theoretical sampling with maximum variation.

Participants were invited to engage in interviews conducted by the investigator and ranged between 2½ and 4 hours in length. Participants included the parent caregivers who were actively involved in making the decision for possible residential group home placement. Each interview was compared and contrasted with all those that came before it in an ongoing, constant comparative analysis. There was comparison of concepts, constructs, and themes to other concepts, constructs, and themes in the interview data for differences and similarities.

Grounded Theory is an inductive process, meaning the researcher does not begin with a hypothesis about the phenomena under study. Rather, the researcher allows the emergence of the theory from the data (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The theory is grounded in the data. In earlier years, Glaser and Strauss (1967) described the methodology of Grounded Theory to be theoretically flexible. However, in later years the theoretical perspective was that of symbolic interactionism (Strauss & Corbin, 1990). Glaser was not in agreement with this and criticized the Strauss and Corbin theoretical perspective. Glaser (2007) believed that in its purest form, Grounded Theory did not have a theoretical perspective and that it contradicts the inductive nature of the methodology. Recent Grounded Theorist Charmaz (2006) recognized symbolic interactionism as the theoretical perspective approach to Grounded Theory.

This underresearched area of how parents made the decision about residential group home placement for their adult child with ID/DD was appropriate to investigate using Grounded Theory with a combination of utilization of the Glaserian and Straussian methodologies. The Glaserian and Straussian methodology approach provided for the discovery of problems the participants identified and for finding out how they managed solutions to those problems. Theory can be developed using empirical data and acts of daily social life, including how a

person makes meaning of what is happening to him or her (Hunter, Murphy, Grealish, Casey, & Keady, 2011).

### **Theoretical Framework: Symbolic Interactionism**

The early theoretical underpinnings of Grounded Theory as described by Glaser and Strauss (1967) suggested that it was theoretically adaptable. The theorists' later methodology was informed by symbolic interactionism that was unconditionally the theoretical perspective. The Grounded Theory focus here included: a) beginning with a phenomenon (parents and decision making); b) having identified a problem related to it (decision regarding placement into a residential group home); and c) aiming to develop an inductive theory about it (Strauss & Corbin, 1990).

The theoretical perspective of symbolic interactionism focuses on the human experience. Blumer (1969) described symbolic interactionism as a theory of human life and human conduct, focusing on the various social aspects of human action and interaction. According to Blumer, the way humans respond or react to things depends on the meaning that things have for them. The meaning that things have for humans comes from their experiences and social interactions with others and their interpretation of the experiences. Grounded Theory was appropriate for studying this phenomenon because little is known in this population about the nature of action and interaction in the decision-making process as a phenomenon. Grounded Theory provides the researcher with a theory that accounts for a pattern of behavior that is relevant and problematic for those involved (Glaser, 1978). The basic building blocks for Grounded Theory are the concepts grounded in the data.

Grounded Theory is an action/interactional-oriented method of inductive theory building that describes and explains the behavior or system under study. It therefore is a methodology for

developing theory. The theory development is grounded in data that are systematically gathered and analyzed (Strauss & Corbin, 1994). The main feature of Grounded Theory is the method of constant comparative analysis with the data collection and analysis occurring concurrently (Glaser & Strauss, 1967). Constant comparison of the interview data is how the theory was developed. Each interview was compared and contrasted with all those that came before it. The interview data were compared for differences and similarities.

In this study, the discovery of the basic social problem of Caregiver Readiness, and a core concept CAREGIVERS CANNOT BE CAREGIVERS FOREVER, informed a substantive theory that described and explained how parents made residential group home placement decisions for their adult child with ID/DD. During data analysis, the core concept occurred frequently in the data with other categories related and attached to the main core. The core concept is the central idea that emerges from the data and is able to explain variation in the information. The core concept occurs repeatedly in the data and is central and relates to other categories with ease and meaning (Glaser, 1967). During the data collection and analysis, the core concept should initially be abstract enough to allow for the development of a general theory (Strauss & Corbin, 1998).

Development of a core concept in this study informed a substantive theory that identified how parents made residential group home placement decisions for their adult child with ID/DD. The limitations of this method included that only the experiences of the parents were explored at a specific moment in time. It may be necessary in future studies to include repeated contact with the parents over a period of time to elucidate the experiences that are not limited to a snapshot in time (Penrod & Dellasega, 1998).



### **Follow-up Interview**

Each participant of the study was asked to engage in more than one interview that included a face-to-face interview and an additional follow-up telephone interview. Both interviews consisted of the life experience of the decision. The second interview conducted by telephone allowed the participants an opportunity to see if they recognized the researcher's findings as to what their words meant as conveyed during the initial digitally recorded interview. The follow-up telephone interview was conducted to revisit the recalled aspect of the decision and to add to the commentary transcribed. All interviewees were contacted; only two did not return repeated telephone messages left by the researcher. This second opportunity was important to provide the repeated contact and methods in qualitative research to assure trustworthiness of the data. It allowed an opportunity for the participants to provide any additional information or correct any error of fact. The interviewees confirmed the researcher's assessments. The researcher performed member checks by sending the verbatim transcripts and portions of interpretative statements to participants who requested it. Only one participant requested the transcript, although all participants expressed an interest in reading the final dissertation document. The follow-up process of telephoning the participants assured accuracy of the original interview and data analysis. However, no participants requested a second interview as offered, nor did the researcher deem it necessary to conduct a second interview with any participant after confirmation of findings with the participants during the telephone follow-up. The researcher also used field notes and memos that enhanced recall of nonverbal or informal communication regarding the experience, and these added to the researcher's perspective of what transpired during each interview.

## **Sampling Methods in Grounded Theory**

Sampling was purposive, theoretical, maximum variation sampling (Morse, 1994) of participants until saturation of the data was reached without any new themes emerging. Charmaz (2006) suggested including 20-30 participants in order to develop a well-saturated theory. Grounded Theory permits concepts and categories to develop during the data collection. Therefore, obtaining participants of specific data sources is necessary until each category has been saturated. At the inception of the study, no limits were set on the number of participants. The researcher continued to interview participants of the study until no new themes were emerging (Cutcliffe, 2000). Using Grounded Theory, a substantive theory for this study was constructed based on accounts of 15 community-dwelling parent caregivers as participants. Sample size was determined when saturation of the data had been reached, and no additional themes emerged.

**Theoretical sampling.** Theoretical sampling is sampling on the basis of concepts that have proven theoretical relevance to the evolving theory. It provides for opportunities to compare events, happenings, and incidents to determine how a category differs in terms of its properties and dimensions (Strauss & Corbin, 1998). Maximum variation aims to capture and describe patterns that slice across heterogeneity, allowing common patterns to emerge that are significant in identifying the core experiences shared among the participants (Strauss & Corbin, 1990). With this in mind, the researcher found it to be necessary to purposively sample and interview a contrary participant in this decision-making process as the data collection evolved and theoretical indication for this emerged.

**Purposive sampling.** Purposive sampling is a non-probability sampling that allows the researcher to select each subject because he or she is considered to be representative of the

population after review of the state of the science. Purposive sampling allowed the researcher to utilize contacts and personal insight when recruiting study participants. The researcher intentionally sought parents associated with several Long Island organizations (see Appendix L) through professional connections and referrals to obtain a wide group of participants. In addition to those parents who have decided for placement, included in the sample was a case where the parent had decided against residential group home placement. This allowed the researcher to more fully understand the phenomenon under study by also exploring the experiences of a parent who had decided against placement.

**Snowball sampling.** Snowball sampling emerged with referrals from initial participants to generate additional participants (Strauss & Corbin, 1990). This type of sampling generates referrals from original participants who know people who could be potential additional participants (Creswell, 1998).

The researcher considered the following participants for the study:

1. Parent participants were selected from organizations in New York located on Long Island that support and provide services to the ID/DD population.
2. Multiple sources of referrals were used in the process of identifying the appropriate sample of participants who met the criteria for inclusion. A variety of services are available to support people as they live independently in their own homes in the community, with opportunity for jobs in the community or attendance at various day programs.

These services include oversight from a registered nurse for all medical needs and follow-up, psychology services, and nutritional support from a licensed nutritionist. Services may be lifelong and include various skill-building opportunities in areas such as safety, personal

budgets, housekeeping, personal care, and nutrition. The researcher sought referrals for possible participants from medical and support team members involved with the ID/DD population such as RNs, psychologists, and nutritionists.

**Maximum variation.** Maximum variation occurred with the utilization of various organizations that support the population with ID/DD. Sampling different ages, gender, developmental disability type, geography, and number of children in the family (see Appendix K and L) allowed the researcher to decide which types of concepts to attempt to maximize in the experiences of the participants (Strauss & Corbin, 1990).

### **Inclusion/Exclusion Criteria**

**Participant inclusion criteria.** To be included in the study, the participant had to define his or her relationship with the person with ID/DD as that of a “parent caregiver” who has been actively involved in making the decision regarding residential group home placement for the adult child with ID/DD. Parent participants for the study included biological parents, step-parents, or adoptive parents. Because the purpose of the study was to explore how the decision regarding placement was made, those parents who made the decision for residential group home placement were included. Placement occurred in an Intermediate Care Facility (ICF) or Individualized Residential Alternative (IRA). At the time of the interview, parents had already placed their adult child with ID/DD in the residential group home at least one month before and not more than five years before the interview. Those who fit that timeframe were included in the study. At least one month gives the parents adequate time to have lived through the immediate transition to talk about the experience in retrospect. Five years since placement allowed the participants a period of time long enough to reflect about their decision-making experience. However, one month to five years was a brief enough period of time to accurately remember the

decision-making experience. In addition, in order to enable the researcher to fully understand the phenomenon under study, the experiences of a parent who has decided against residential group home placement was also explored through interview.

Therefore, based on the review of the literature and the significant gap identified, the sample included parents of the adult child with ID/DD who were involved in the decision making regarding residential placement and had placed their adult child in a residential group home. In addition, to explore the contrary case or theoretical discrepancies in the phenomenon, a parent who decided against placement was included. Participants were English-speaking and able to hear at a conversational level to allow for accurate data collection.

**Participant exclusion criteria.** Parents with adult children with ID/DD who were on a list waiting for residential group home placement were excluded from participating in the study. Parents of adult children with ID/DD who had expired since placement were not included. Also excluded from the study were parents who had placed their adult child with ID/DD more than five years ago and less than one month previous. Additional exclusion criteria were those adult children with ID/DD who were placed in a residential group home setting directly from an institutional facility such as a state-operated facility or school, as well as those who placed but no longer resided in the residential group home.

### **Recruitment**

After IRB approval from Molloy College and a letter of support from the involved organizations, the researcher initiated contact with healthcare directors, directors of nursing, medical social workers, service coordinators, operation directors, associate divisional directors, divisional directors, Medicaid service coordinators (MSC), and the admissions department of the organizations for potential parents to participate in the study. Discussion for possible

participants occurred with members of the admissions teams of the Long Island-based organizations. In addition, permission was obtained from the participating organizations to advertise with community organizations. The strength of this type of sampling was that multiple healthcare professionals, other than just the researcher, identified subjects for participation. The researcher reached out to various contacts in organizations including Community Mainstreaming Associates (CMA), Association for the Help of Retarded Children (AHRC) Nassau, Family Residences and Essential Enterprises (FREE), Mary Haven, and Life's WORC for potential participants and requested their assistance in the distribution of fliers. Fliers about the study (see Appendix E) were distributed and posted in the organizations' various locations. Fliers were distributed at locations where family support meetings were offered by the participating organizations as well. The distribution of fliers was successful in obtaining participants. Although the criteria were clearly delineated on the flier, several parents who placed their adult child over 10 years ago expressed interest in participating. The researcher declined their participation for this particular study. However, these potential participants will be invaluable for future studies conducted by the researcher. In addition, other contacts were sought from community organizations such as day programs and programs without walls, and an occupational training institute that provided services and support to individuals with ID/DD. The leaders of other Long Island organizations that support people with ID/DD were approached to enlarge the potential sampling frame outside of the researcher's own organization. Additionally, participants who were included were without a direct relationship with the researcher's organization of employment. It is important to note that, although the researcher is the Director of Integrated Health Care at Family Residences and Essential Enterprises, Inc. (FREE), the contacts did not jeopardize the volunteer aspects of the study and participants were not interpersonally involved

with the researcher. The researcher's role at FREE did not involve direct relationship with the interviewees.

Participants were selected through the researcher's professional contacts with various team members of the selected organizations. This type of recruitment allowed for snowball sampling to naturally occur. Additionally, participating parents helped to generate and recruit additional interested study participants. The researcher attended organizations' regularly scheduled family meetings whenever possible where the researcher identified herself as a Ph.D. student and explained the research study. Attendance at these meetings allowed for an opportunity to announce and advertise the study.

Initial screening for eligibility of interested participants occurred by a telephone screening conducted by the researcher. The telephone screening (see Appendix H) allowed the opportunity for the researcher to discuss the interview process and determine the interest and eligibility of the potential participant. An initial interview was scheduled if the interested participant met the eligibility requirements and remained interested in participating. The researcher strived for individual interviews, but allowed for dyads as needed or requested by the participants. One of the interviews was a dyad consisting of a husband and wife participating and each participant was counted separately in the total number of interviews.

### **Individualized Residential Alternative/Intermediate Care Facility**

Two different types of 24-hour supervised homes are operated by the Office for People with Developmental Disabilities (OPWDD). The type of housing necessary to safely support the individual with ID/DD in the community is determined early in the screening process. Historically, the choice of home for placement is based on the variation of supports needed; the difference usually involves a difference in how the home is funded as well as how the provided

services are billed. At this point in time, many of the current Intermediate Care Facilities (ICFs) are being converted to Individualized Residential Alternatives (IRAs). In the current climate of the service system of OPWDD, these homes are being converted to transform the supports and services it offers to people with ID/DD, ensuring that each person receives services in the most integrated, person-centered model. The selection of study participants for this research was not based on which of the two programs they resided in, but rather the parent caregivers were purposively selected because they had an adult child with ID/DD who resided in one or the other of the 24-hour OPWDD-supervised homes.

The IRAs and ICFs are two different types of residential group home settings. These homes are funded differently and the services are billed differently. Many agencies have recently converted ICFs to IRAs to make it easier to provide more individualized services to the individuals who live there. A major difference between the IRA approach and the ICF is that in the IRA, there is a separation between the residence and the services required by the individual living there. Under the ICF model, the type of services offered often dictates the setting. Under the IRA, the primary focus is on the individual and his or her particular needs, wishes, and requirements. In an IRA, the individual will receive services that are considered separate from housing. Such services, known as home and community-based services, may be billed to Medicaid. Those individuals residing in an IRA may apply for the home and community-based services (HCBS) waiver program. When in the program, the individual is assisted in selecting a service coordinator who will act on his or her behalf. A service coordinator can be chosen from any agency that is authorized to provide service coordination. It is the responsibility of the service coordinator to identify the services that the individual needs or desires, and to develop an individualized service program (ISP). Services can include necessary medical providers,



including coordination of a primary care provider, specialty physicians, physical therapy, occupational therapy, speech therapy, medical insurance, day programming options, counseling services, and any other supports identified by the interdisciplinary healthcare team. Interviews conducted with parents who have placed their adult child with ID/DD in either of these settings provided valuable, rich information.

It has been the researcher's experience that parents are often influenced by the type of home, location of the home, types of services provided, the staff who work in the home, other individuals who already reside in the home, parents or families of those already residing in the home, physical environment of the home, as well as additional factors that are considered prior to making a decision. The research of this phenomenon explored and described from the emic perspective many of these external precipitating factors, as well as identified others factors that could potentially affect the decision for placement.

### **Setting**

As described in a study conducted by Penrod and Dellasega (1998), interviews were scheduled to accommodate the schedule and travel needs of the participants. The interviews were held in a location that allowed for privacy during the interview process. The interviews were done in a mutually agreed-upon location that was private, where confidentiality could be assured. Participants were able to select the location for the interview that allowed for privacy with attempts to limit possible interruptions during the interview process. It was encouraged to have a setting for the interview where conversation could remain private and digital recording could accurately occur. Interviews could also be conducted at the parent caregiver's home or any mutually agreed-upon location that was appropriate and comfortable for the participant. After completion of an interview, each interview was analyzed before conducting the next. Each

interview was compared to all that had come before prior to completion of the following interview.

### **Data Collection Procedures in Grounded Theory**

After determining the research question, the investigator developed a semi-structured interview guide (see Appendix C) with probes. It was drafted from a concept map (see Appendix D) which helped to determine the focus of inquiry. Consent (see Appendix A) was obtained from the parents and included the purpose of the study; informed the participants that the study was voluntary and that they had the right to withdraw at any time; indicated the risks and benefits of participation, the names of the institution and of the principal investigator, and who to contact with questions and concerns; and described the possible use of the data for secondary analysis in future research, and measures to provide for confidentiality. The consent form was written at a sixth-grade reading level. The inclusion of a demographic inventory was used to acquire descriptive statistics of the participants (Strauss & Corbin, 1990). Demographic data were collected, including participant characteristics of gender, age, marital status, and education that will help the reader to identify the population from which the sample was drawn (Morse, 1991) (see Appendix B and Appendix K).

### **Interview Procedure**

The researcher conducted interviews with the participants one at a time. The interview guide used was a semi-structured set of questions developed with broad areas of inquiry, leaving room for in-depth exploration that the participant could initiate if it were meaningful. The purpose of the interview guide was to assist the interviewer in asking questions to the interviewee that addressed the phenomenon under study without forcing answers to a series of questions that were prescribed. The attempt was to describe the phenomenon from the

perspective of those who were experiencing it. The “emic” perspective allowed the participant to respond to the open questions by sharing content that was most relevant to him or her. Prior to beginning the data collection, the researcher attempted to bracket any personal bias, perspectives, attitudes, and beliefs (Rubin & Rubin, 2012). The interviews were conducted by the same interviewer, recorded with a digital recorder, and transcribed verbatim by a transcriptionist. Participants were given a gratuity of a 10-dollar gift card for their time and participation in the study.

### **Data Collection**

The collection of verbal and nonverbal data occurred simultaneously with the inclusion of memos and field notes. The interview guide questions had been designed to obtain rich in-depth descriptions of the phenomenon. Several of the questions had probes that encouraged the interviewee to elaborate further, enabling the interviewer to gain a deeper, richer understanding of the concept. A demographic inventory (see Appendix B) was used to acquire descriptive statistics of the participants (Strauss & Corbin, 1990). Demographic characteristics of gender, age, marital status, and education helped the reader to identify the population from which the sample was drawn (Morse, 1991).

**Field memo sheet.** Immediately following the completion of each interview, the researcher utilized a field memo sheet (see Appendix F). This was filled out by the researcher and used in conjunction with the analyzed data to add to the richness of the information gathered. The field memo sheet provided the researcher with an additional way to identify any main issues or themes that were significant during the interview. The researcher handwrote the field memo immediately after completion of each interview. This immediate scribing of notes provided the opportunity to write down any salient, interesting, and illuminating information. The field notes

also provided direction for subsequent interviews. In addition, it fostered the ability to summarize information that was obtained or not obtained on each target question, including possible salient points, themes, and codes. More importantly, it was an extremely useful tool for the researcher to determine what new or remaining questions she would have for the next contact with the participant for a follow-up telephone interview after the original interview, as well as with other new participants interviewed. The researcher also referred to the field memo when follow-up telephone contact occurred with the participants. Twelve of the 15 participants were reached by telephone, and the researcher's assessments of the interviews were discussed. Based on the outcome of the telephone interviews, there was no need to schedule any additional face-to-face interviews.

**Memos.** During the interview, the researcher wrote memos that linked coding and theory development. The memo process (operational and theoretical) allowed the researcher to write down thoughts regarding the data at the time of collection and aided in developing an audit trail. Theoretical memos represent the researcher's ongoing record about how the theory was developing. Operational memos recorded the methodological decisions and problems encountered during the interview process (Lincoln & Guba, 1985).

**Field notes.** Field notes were dictated immediately following the interviews and represented the researcher's "reaction" to the interview. The field notes and memos contained supplemental information about the interview process and emerging theoretical insights and were included in the data set (Strauss & Corbin, 1990). The conceptual level of the ideas and thoughts can then be elevated towards developing a theory (Glaser, 1978). The additional information the researcher gathered from field notes added content, understanding, and meaning to the transcripts

and other data collection methods. The utilization of this information was vital for the development of a substantive theory.

### **Data Management**

Only the researcher and the contacts at the organizations knew the identity of the parents who agreed to participate in the study. Pseudonyms were given to all participants and were contained in the transcripts. Prior to transcription, the researcher discussed with the transcriptionist the ethical handling of the data and the need to maintain confidentiality. A signed confidentiality statement (see Appendix E) was obtained from the transcriptionist before transcription began. The names of participants, transcripts, and all relevant documentation, and a digital card for the recorder were maintained in the researcher's office securely locked with a key to which only the researcher had access.

### **Data Analysis**

The goal of data analysis is to describe, explain, or predict about a phenomenon by conceptualizing beyond the individual participants to represent a group experience. During data analysis, the researcher stayed close to data, reporting the person's subjective experience. The constant comparative analysis of the data occurred until saturation was reached (Rubin & Rubin, 2012). Analysis of the data was used to develop concepts and describe themes common to the participants. Using constant comparative analysis, the interview data were reviewed to identify common threads within the reported experience (Glaser & Strauss, 1967). Insights gained from this process helped to inform the development of theory. In addition, theoretical sampling allowed the researcher to complete ongoing data analysis providing for identification of themes or the potential direction of the data. The potential direction can be utilized to select new participants or interview questions to gather specific data (Strauss & Corbin, 1990). The semi-

structured open-ended interview questions were used as a guide for collecting information. The participants elaborated with minimal prompting and use of probe questions. No new formal questions needed to be created to elicit information. Purposive sampling involves specific decisions to sample particular participants and to continue seeking additional interviewees that will contribute to the overall understanding of the phenomenon (Cutcliffe, 2000). In addition, reviewing the literature assisted with the concept analysis, the linkage between the interview guide questions, and the shared decision-making framework (see Appendix J).

**Transcription of data.** Analysis of the raw, digitally recorded data included verbatim transcription of all the interviews by a transcriptionist. Field notes and memos for each participant interview were handwritten and reviewed by the researcher and dissertation committee. All vocalization was transcribed phonetically, allowing for nonverbal expression not to be lost in the transcription so that the text accurately captured the interview. Data were transcribed as soon as possible after the interview was conducted, which allowed for initial coding and possible categories to begin to be identified (Strauss & Corbin, 1998). After transcription of the digital audiotapes was completed, the researcher reviewed the transcriptions while listening to the audiotape to clarify any parts of the interview that may have been unclear to the transcriptionist (Penrod & Dellasega, 1998).

**Coding of the data (In Vivo and NVivo).** Interview transcriptions were analyzed using In Vivo open first-line Level I coding of the data. Line-by-line coding was accomplished using open coding of the transcripts, notes, and memos. Line-by-line open coding allows the researcher to identify substantive codes emergent within the data. The researcher continues to ask questions of the data, exploring a) what those data is a study of; b) what category the incident indicated; c) what actually happened in the data; and d) what accounts for continued resolution

of this concern. As the researcher continued the inquiry of the data, it allowed her to remain sensitive and transcend theoretically while analyzing, collecting, and coding the data. Asking questions of the data allowed the researcher to look conceptually beyond the detail of the data. The researcher coded into categories and continued to develop categories as they emerged from the data. The emergent theory was grounded in the data while open coding allowed the researcher to generate codes and categories that could be handled theoretically. The researcher formed initial categories of information about the phenomenon being studied. She generated as many codes as possible to fit the words of the participants. Within each category, she searched for properties or subcategories. After coding the interviews at Level I, attempts were made to identify themes and advance to Level II coding. Level II coding clustered similar data incidents, grouping them into categories, followed by Level III axial coding that allowed coding around one core concept, category, and the specific conditions that fit with the interaction. Level III axial coding allowed for connections to be made between categories (themes) that may blend into concepts and link a theory that is explanatory (Strauss & Corbin, 1990). The codes were used as labels to assign meaning to the data. An example of the coding process used for the theoretical construct of *normalcy* is illustrated in Table 1.

When coding the interviews, in order to become familiar with the data, the researcher read the interviews more than once in order to reflect on what was experienced during the actual “live” interview, as well as listened to the recorded audio. After open coding, connections were made between categories (themes) using axial coding. Theory was inductively produced from themes grounded in the data consistent with the Grounded Theory methodology. The core variable was essentially the main theme that explained most of the variation in the data and linked the various data together. It addressed the basic social problem that the participants faced

Table 1

*Example of the Coding Process of the Theoretical Construct: NORMALCY*

Level I Code	Level II Code	Level III Code	Core Concept	Basic Social Problem
Independent Confident Same age Peers Cooking Co-workers Laundry Holidays Disagreements Sharing Compromise Shopping Self-care Bed making Baking Celebrations Relationships Job Developing Enjoyment Rules Annoying Fair Similar Friends Self-actualized Collaborate Emotions Crafts Decorating Altercations Entertain Grow Positive Enjoy Lucky Dances Activities Happy Goals Interacting Gym Church Temple Companion	Fear of missed opportunity  Now they have their own life unlike before  Have their own thing  Employment  A sense of home  "Band of brothers"  They move on  Marriage  They don't feel alienated  "Regular" home  Two homes  Like everyone else  Exposure to other things  Fend for themselves  Interest in the opposite sex  Same problems  Go out for meals  Treated as adults  Good for them to do  Do not want to live with parents forever  Celebrate holidays	Normalcy	PARENTS CANNOT BE CAREGIVERS FOREVER	Parent Caregiver Readiness



and attempted to resolve or explain their problem. The identification of a core variable and the basic social problem is the goal of Grounded Theory analysis and theory development (Strauss & Corbin, 1990).

Grounded Theory methodology reveals the core social process. The core process is shared and experienced by the participants in the research study (Cutcliffe, 2000). Extending from this process are the categories/theoretical constructs (building blocks of the theory), conditions, consequences, and strategies used by parent caregivers as they made the decision regarding residential group home placement for their adult child with ID/DD (Strauss & Corbin, 1998). This qualitative method was appropriate for this investigation because the aim of this research question was to understand how parents made the decision for residential group home placement for their adult child with ID/DD and these persons shared a basic psychological problem.

**NVivo computer software.** NVivo (Qualitative Research Software: QSR International, 2013) computer software program was used for organization and management of the data. NVivo is a computer software program that supports qualitative and mixed methods research. It is designed to handle non-numeric data such as interviews, open-ended survey responses, and literature reviews and internet content; in addition, it has the capability of taking in numeric data. Regardless what qualitative research method a researcher uses when handling qualitative data with the use of the software, subtle connections will be discovered within the data collected using the software.

NVivo computer software gave this researcher a place to organize and manage data. This allowed her to begin making sense of the data. The NVivo software provided tools that allowed the researcher to ask questions of the data in a more efficient way than would be possible

manually. Once the data had been collected with NVivo's data analysis process, the researcher imported data from a variety of places including participant transcripts, field notes, and theoretical memos. The software allowed for the creation of "nodes" in which to store data. When grouping data into nodes, the researcher looked for words and themes used most frequently in the data. The NVivo computer software allowed the researcher to efficiently visualize what the data were saying all in one place. It allowed her to organize, store, and retrieve data, allowing connections to be uncovered in ways that are difficult to accomplish manually. The result of aggregating collections of phrases that could be shared with dissertation committee members provided an efficient mechanism for discussions of themes and expressions that emerged from the transcripts. A limitation was that NVivo computer software offers minimal assistance in actual data analysis; however, it was extremely efficient for data management (Qualitative Research Software: QSR International, 2013).

### **Human Subject Considerations**

**Potential risks to the participants.** The study posed little threat of harm to the participants. However, the risk of emotional duress during or after the interview process was possible. The availability of counselors was made known to the participants. A referral list of counselors and their contact information would have been provided professional counseling services if needed. One of the participants asked the researcher for guidance on the availability of services, and she was referred to a family advocacy support group. The participants could withdraw from the study at any time without any consequences. The potential risk of being able to maintain confidentiality of the information provided by the participants existed. Safeguards were put in place to protect confidentiality of all information. Only the researcher and the contacts at the organization knew the identity of the parent caregivers who agreed to participate

in the study. Pseudonyms were given to all participants and were maintained in the transcripts. All information was de-identified. The participant selected a private setting of their choice for the location of the interview.

**Potential benefits to the participants.** There were no direct benefits to the participants. However, the potential benefits of the study involve the contribution that the findings provide in addressing and filling the current gap in nursing research literature and nursing knowledge on the subject of parental decision making regarding placing adult children with ID/DD in residential group homes. This new knowledge may help assist other parents who face the need to make similar decisions. Another possible benefit was that, through the interview process, the discussion with the researcher may reinforce with the parents the appropriateness of their decision for residential group home placement or conversely the decision not to place their adult child with ID/DD.

### **Institutional Review Board**

**Consent.** Prior to data collection, Molloy College Institutional Review Board (IRB) approved the research as non-exempt, expedited status. The semi-structured interview guide was provided to the IRB with the understanding that the researcher would personally be conducting the interviews. The IRB was informed that the line of inquiry may need to change during the project in response to what the interviewees told the researcher as the qualitative interviews evolved (Rubin & Rubin, 2012). The semi-structured open-ended interview questions allowed for adequate prompting of the participants. There was no need to formally change the interview questions. A letter of support and permission to advertise with a flier were signed by the New York, Long Island organizations' Board of Directors which provide services and supports individuals with ID/DD and where the parents were sought out for participation in the study. A

consent form with a written explanation of the study was provided for the parents that included: the purpose of the study; the voluntary nature of the study and the participants' right to withdraw at any time; the risks and benefits of participation; Molloy College's listing as the institution with which the principal investigator was affiliated; who to contact with questions or concerns; and measures to provide for confidentiality. Parents completed and signed the consent, acknowledging that they were willing to participate in the research study. Informed consent was obtained from the participants prior to the researcher conducting any interviews. The consent was written at a sixth-grade reading level. Participation in the study was entirely voluntary and participants were given the opportunity to ask questions prior to, during, and following the interview. The participants gave consent to be interviewed, which included the ability for the participant to withdraw from the study at any time. The name and telephone number of the researcher was listed on the consent. The intent of the study and possible future publication was explained in the consent. The participants could contact the researcher for the results of the completed study. In addition, the consent included disclosure that this investigator, or another investigator, may wish to use the de-identified data obtained in a future secondary analysis to answer a new research question. No names or identifying characteristics were used in the study, the interviews, or during analysis of the data. If at any time during the interview process the participant expressed concerns about the care of their adult child with ID/DD, the appropriate professional people and organizations would have been notified immediately. If at any time the participant expressed distress, a list of counselors and their contact information would have been provided for the participants.

## Scientific Adequacy

In qualitative research, scientific rigor is the process of reducing the personal bias of the researcher in their study. Distortion in the results of a study can be the result of bias (Polit & Hungler, 1997). Through the rigor of the planned protocol, the goal of trustworthiness is what the qualitative researcher strives to obtain to support the findings so they are considered valid. Validity is the ability to see cause and effect in the study's findings, and to generalize the findings (Nieswiadomy, 1998). Trustworthiness is defined as the credibility, transferability, confirmability, and dependability of the research findings (see Appendix M) for the summary of trustworthiness in qualitative research. The four terms—a) credibility, b) transferability, c) confirmability, and d) dependability—are the naturalist's equivalents to the conventional quantitative research terms of a) internal validity, b) external validity, c) objectivity, and d) reliability.

Guba and Lincoln (1981) identified four key concepts that all researchers need to consider in order to establish rigor in research. These are as follows:

**1. Credibility:** Truth value can be described as established confidence in the “truth” of the findings of a particular inquiry for the participants and the context within which the inquiry was carried out. Truth value (credibility) was established with the use of prolonged engagement, persistent observation, triangulation, expert debriefing, negative case analysis, member checks, field notes, rich excerpts, and consultation with experts (Guba & Lincoln, 1981, pp. 103-104). Member checks were completed by returning to the original participants for verification of their interview data (Guba & Lincoln, 1981). Interviews with participants were conducted over a 15-month period of time. Each participant interview lasted approximately 2½ to 4 hours, generating a total of 632 pages of transcript data. The researcher performed “member checking”

during initial data collection and by conducting follow-up telephone interviews with participants. The follow-up telephone interviews determined if the findings the researcher had discovered were an accurate reflection of the participants' own experience. Follow-up telephone conversations also provided an opportunity for the study participants to validate or correct the information from the researcher's initial interview. As well, it provided an opportunity for the researcher to increase the depth of the data and attempt to close gaps in the emerging analysis (Morse, Barrett, Mayan, Olson, & Spiers, 2002). However, following the follow-up telephone interview of 12 of the 15 participants, no participant requested a second face-to-face interview, nor did the researcher deem it necessary to conduct a second face-to-face interview. Three participants did not return repeated telephone messages left by the researcher for request for them to participate in a follow-up interview. Additionally, the researcher used her field notes and memos to enhance the experience and to recall nonverbal and/or informal communication from the participants regarding their experience.

Consultation and debriefing occurred with experts Dr. Veronica Feeg and Dr. Susan Vitale at Molloy College and Dr. Diane Pastor at the University of North Carolina, Wilmington before and during data collection, and when data analysis was occurring. During these debriefing sessions, collaboration occurred while the data were reviewed and discussion transpired regarding any methodological matters, data analysis, dissertation progression trajectory, and any other identified matters to be addressed.

**2. Transferability:** Applicability, also known as transferability, is explained as the degree to which the findings of a particular inquiry may have applicability in other contexts or with other subjects. Transferability of the findings was supported with thick description, maximum variation sampling, and summary of sample characteristics (Guba & Lincoln, 1981,

pp. 103-104). In this study, interviews were conducted that resulted in transcripts from each participant including rich, thick, descriptive data. Maximum variation occurred by including parent caregivers who would provide a range of participants of the phenomenon under study. Theoretical sampling of participants provided for parent caregivers who had experiences within the phenomenon being studied. In addition, the researcher provided a summary of the participants' demographic information. All of these strategies assisted in the determination of transferability.

**3. Dependability:** Consistency, or dependability, represents whether the findings of an inquiry would be consistently repeated if the inquiry were replicated with the same (similar) context. Consistency was obtained with the use of memoing, an audit trail, reporting final sampling strategy, field notes, and expert debriefing using audit checks (Guba & Lincoln, 1981, pp. 103-104). This assurance of the consistency of this qualitative research study occurred with members of the researcher's dissertation committee who reviewed all of the data, transcripts, field notes, and NVivo-aggregated collection of phrases. The dissertation committee members were consulted regularly during the researcher's theoretical coding of the data. The process whereby participants were selected was described and explained. During the research process, the researcher maintained an audit trail by scribing operational and theoretical memos. In addition, she maintained field notes that corresponded to all interviews allowing for the description of contextual elements.

**4. Confirmability:** Neutrality, also described as confirmability, is the degree to which the findings of an inquiry are a function solely of the subjects and conditions of the inquiry and are not of the biases, motives, interests, perspectives, and so on, of the inquirer (Guba & Lincoln, 1981, pp. 103-104). Neutrality was established via member checks, reflexive journaling, and

confirmability audit. The researcher conducted reflexive journaling throughout the research process to reflect on what was happening regarding her preconceptions, values, and interests. The consistent reflexive journaling helped to reduce bias and assisted in the bracketing of personal opinion or potential personal bias. The researcher conferred with the dissertation committee for the review of data on a regular basis. Dr. Diane Pastor and Dr. Susan Vitale, who are method experts in qualitative Grounded Theory methodology, conducted confirmability audits by the initial review of the raw data, review of field notes and memos, as well as a review of theoretical themes, categories, and relationship of constructs.

### **Summary**

This qualitative study used the Grounded Theory methodology. Grounded Theory was appropriate for studying this phenomenon because little is known about the phenomenon of how parents of adult children with ID/DD make residential placement decisions. Participants were invited to engage in interviews conducted by the researcher utilizing a researcher-developed semi-structured interview guide with probes. Each interview was compared and contrasted with all those that came before it with constant comparative analysis. The insights achieved from constant comparative analysis informed the development of theory. The focus was on a phenomenon (parent caregivers and decision making), having identified a problem related to it (possible decision for placement into a residential group home), aimed to develop an inductive Grounded Theory (Strauss & Corbin, 1998).

The sample of this study consisted of 15 participants, including one dyad of husband and wife. Participants included were parent caregivers who were actively involved in making the decision for possible residential placement for their child with ID/DD. Sampling was purposive, theoretical sampling with maximum variation. Subjects were recruited from organizations



located on Long Island that provide support and services to the population with ID/DD. Sample size was determined when no new themes emerged from the data and saturation was reached. The semi-structured interview guide consisted of open-ended questions with probes. The interview included a demographic inventory to acquire descriptive statistics of the participants. Interviews were conducted one at a time by the same interviewer (the researcher) in a private environment. Interviews were recorded with a digital recorder and transcribed verbatim. The data were transcribed phonetically allowing for nonverbal expression not to be lost in the transcription. The researcher performed follow-up telephone interviews with 12 of the 15 participants. The follow-up telephone interviews determined if the findings the researcher had discovered were an accurate reflection of the participants' own experience. It also allowed for the opportunity to clarify or add to the findings. The collection of verbal and nonverbal data occurred simultaneously with the inclusion of memos and field notes.

Truth value was achieved by prolonged engagement, persistent observation, triangulation, field notes, and rich excerpts. Applicability was addressed in the study with thick description, maximum variation sampling, theoretical sampling, bracketing of personal opinion or potential personal bias, In Vivo coding, and summary of sample characteristics. Consistency was achieved with memoing, reporting final sample strategy, field notes, expert consulting, and debriefing. The final question of scientific adequacy of neutrality, according to Lincoln and Guba (1985), was met by member checks, reflexive journaling, and confirmability audit.

Implications of this study may lead to a greater understanding and clarity of this phenomenon and help inform interdisciplinary members of the healthcare team and ID/DD service professionals on the creation of targeted interventions or strategies for this unique vulnerable population. The creation of targeted interventions or strategies can potentially

influence parent decision-making positively and offer direction for further research. In addition, the results of the study can potentially improve transitional care for placement outside the family home for the ID/DD population. Furthermore, the study findings could influence health policy by future policy development that recognizes the need to support those skills to achieve a positive outcome for the parent caregivers, as well as the adult child with ID/DD they care for, within the constraints of the current healthcare system.

## **Chapter 4: RESULTS**

### **Introduction**

The purpose of this Grounded Theory study was to develop a substantive theory that would describe and explain how the parent caregivers of the adult child with ID/DD made the decision for residential group home placement.

The participants of the study included 15 parent caregivers of adult children with ID/DD. One interview consisted of one dyad of a husband and wife; therefore, 13 of the parent caregiver participant interviews were with parents who had made the decision for residential group home placement for their adult child with ID/DD. In order to better enable the researcher to fully understand the phenomenon under study, the experience of a parent who decided against residential group home placement was explored through interviews. The parents' ages at time of interview for this study ranged from 52 years of age to 71 years of age. Participants were English-speaking, 14 Caucasian and 1 Hispanic, and resided on Long Island in their own residential home.

The group of participants included parent caregivers who had already placed their adult child with ID/DD in a residential group home ( $n = 14$ ), and a parent who decided against residential group home placement was explored through interview ( $n = 1$ ). Mean age of the parent caregivers was 62.1, mean duration of caregiving across the group was 25.1 years, mean duration of years since placement across the group was 3.8 years. The summary of the parent participant and child pseudonyms, gender, and age are presented in Table 2.

Table 2

*Parent Participant and Child Pseudonyms, Gender and Age*

ID #	Pseudonym: Parent	Gender: Parent	Age: Parent	Pseudonym: Adult Child	Gender: Child	Age at Placement: Child	Years Cared for at Home
1	Patricia	Female	56	Carla	Female	26	26
2	Javon	Male	62	Edward	Male	21	21
3	Catherine	Female	52	Samantha	Female	22	22
4	Illyse	Female	66	Peter	Male	23	23
5	Emilia	Female	71	Carmine	Male	37	37
6a	Betty	Female	65	Laura	Female	20	20
6b	Raphael	Male	71	Laura	Female	20	20
7	Jennifer	Female	62	Theodore	Male	23	23
8	Rita	Female	57	Racquel	Female	22	22
9	MaryAnn	Female	70	Marissa	Female	20	19.5
10	Karen	Female	56	Kristen	Female	23	23
11	Edie	Female	63	Robert	Male	25	25
12	Debra	Female	59	Stanley	Male	22	22
13	Talia	Female	54	Angela	Female	26	26
14	Valerie	Female	67	Joey	Male	N/A	N/A

**Legend:**

**N/A** = Not applicable (did not place child)

Additional demographic information can be found in Appendix K. Of the 15 participants, 14 had decided on residential group home placement, and one parent decided against residential group home placement at this time for their adult child with ID/DD.

Participants invited to be involved in the study were from five various Long Island organizations that provide services to persons with ID/DD. Twelve of the parents who participated were the mothers of the adult children with ID/DD, one interviewee was the father, and another interview consisted of the mother and father participating in the interview process. All the adult children of the participants had a diagnosis of ID/DD (see Appendix U).

### **Basic Social Psychological Problem**

The READINESS of the parent caregiver was identified as the basic social problem and PARENTS CANNOT BE CAREGIVERS FOREVER was identified as the central process, or core concept, of residential group home placement decision making. Four theoretical constructs, their related contextual and intervening conditions, and the distinct management strategies and responses of parents and their adult children with ID/DD were discovered in making a residential group home placement decision.

### **Core Concept**

The core concept identified through this qualitative inquiry of the data was PARENTS CANNOT BE CAREGIVERS FOREVER. This explained residential group home placement decision-making management as a process of perceived readiness for parent caregivers of those with ID/DD.

### **General Description of Data**

The purpose of this Grounded Theory study was to develop a substantive theory that would describe and explain how parent caregivers make residential group home placement

decisions for their adult child with ID/DD. Parent CAREGIVER READINESS was identified as the basic social problem and PARENTS CANNOT BE CAREGIVERS FOREVER was identified as the core concept, or the central process of residential group home placement decision making.

### **Answering Research Question**

The findings answering the research question are presented in several sections. First, the conceptualization of the Basic Social Problem, CAREGIVER READINESS, is explained. Then, an overview of the core concept, PARENTS CANNOT BE CAREGIVERS FOREVER, is presented. In the next four sections, the four theoretical constructs, their related contextual and intervening conditions, and the distinct management strategies and responses of parents and their adult children with ID/DD are explicated and illustrated.

**Basic Social Psychological Problem: Caregiver Readiness.** The participants of this research study used a variety of resources to help themselves arrive at a decision for residential group home placement. Several seemed to suffer through the process while others seemed to have an easier time. Many intervening factors and emerging themes were identified during the interviews. However, the common thread woven throughout the data and identified as the basic social psychological problem was *caregiver readiness*. Caregiver readiness to make the residential placement decision for their adult child with ID/DD was identified as the basic social psychological problem. Considerable attention has been directed toward caregivers of acute and chronically ill individuals; however, there is limited information specific to parents who care for the ID/DD population. *Caregiver readiness* to make residential placement decision as conceptualized in this study is defined as the perceived awareness and preparedness of the

parents to make a decision about residential group home placement for their adult child with ID/DD.

Caregiver readiness exemplified and influenced the caregivers' decisions over time. The parent caregivers had intervening theoretical constructs and conditions that precipitated their decision; however, they were unable to forge forward in the decision process until *caregiver readiness* was reached. Caregiver readiness was influenced by the recognition of several theoretical constructs that were affecting their ability for decision making. These theoretical constructs included the parents' desire for normalcy for their adult child with ID/DD; the concern of future burdening of the siblings of the adult child with ID/DD with the caretaking responsibility; parent realization of their own mortality and the need for future planning; and the recognition of the benefit of a support system during the decision-making process. The degree of readiness is illustrated in the participants' quotes that follow.

### **Caregiver Readiness: Research Participants**

**Patricia.** Patricia was a 56-year-old married mother of four children and a registered nurse. She struggled with being ready to make the decision for residential group home placement after caring for her daughter who has Down syndrome for 26 years at home. This mother said she had "devoted her whole life" to her child. The family discussed the inevitability of residential placement and the many variables that required consideration when making the decision and the need for them to feel ready to do so. The parents struggled to pick the best house, where the child fit in.

*So then in about six months after that somebody else comes in and says "Oh you know, I was thinking about it, she certainly fits in this house, but if you're not in a rush we're going to be opening another house and we think she'd be a better fit. If we put her in this house," the one in East Meadow, "she's going to be one with the optimal functioning. She won't have a role model. In the other house she's kind of fall right in the middle where there would be people who would be learning from her and she'd have people that*

*she could learn from.” I said, “I’m not in a rush. Let’s go with the second one.” She goes, “Well, I have to let you know, it hasn’t even been purchased yet.” I said, “I don’t care. I’m not in a rush.” . . . They found the house eventually. It took a while to get it open and that’s where she is. And during the course of that I had to convince my husband we were doing the right thing at the right time because Carla is and was the apple of his eye. That was his baby. Because all of those years I was going to school and working nights, all that kind of stuff after she was kind of established he was the one who was providing the hands-on care, that was home when she came home from school. That’s his baby. When she was born he said, “She’s going to be my baby forever.”*

Patricia and her husband were very involved and planned for the decision; however, when the time came for Carla to move into the residential group home setting, they were surprised at their own reactions. Patricia’s husband had a special bond with his daughter, often being the caregiver, and experienced an even more difficult time after the decision for placement was made.

*It was very traumatic. It was a traumatic decision for both of us in a way. Less so for me because I know what was going on in the houses. More so for him because he really was not ready to let go and he said to me, “Well what am I going to say when she calls up and says come pick me up now?” And I said, “Don’t worry about it. She’s going to be really happy. And if she does, just say, talk her through it and go from there.” The day we dropped her off, oh that was heartbreaking.*

**Javon.** Javon was a 62-year-old married male and father of two children who cared for their child with autism spectrum disorder at home for 21 years. This family had actual hands-on experience in the development, buying, and renovation of the child’s placement house. They jumped in and took charge of the future housing for their son. The parent indicated that the family kind of knew early on that the child would need placement, so they not only realized they wanted placement but took control of it. While their son lived at home, he spent the summer at camps where he thrived. The parents saw this as a sign that he would do well in the future in a residential setting.

*That was an indication to my wife and I that Edward probably would do very, very well in a group home setting and we set out to begin to explore that.*



There was a moment in time when the dynamics of the family began to change. Edward became aggressive. The family began to experience a lack of control and recognized their inability to safely manage their son at home.

*We had a live-in housekeeper who was with us for 20 years, which enabled both of us to maintain our professions and provide safety and security for both the kids, but particularly Edward . . . she would get on the phone to find out what we were in store for when we walked through the door. . . . We're educated people, I guess it's the long way of getting back to the fact that people say, "How do you and your wife do this? How do you manage it?" And our response has always been, "We don't know any other way." I don't know how I knew. It brings tears to my eyes. I just do it. And then you have to put that into perspective that there are a whole bunch of other people that don't know how to do it. It's not instinctual to them. Whatever their circumstances are, they don't know how to deal with it. They're less educated. They've grown up in a different environment. . . . That was the dynamic until things changed from an emotional perspective . . . but it changes you, your disposition changes. I recognize something in myself that my demeanor at work, up until the point he moved out of the house, was classified as type "A" demeanor. And probably six months later, I got this Ah hah. I forget what the heck it was. I said, you know something, you have been behaving a certain way for all these years, and suddenly it suddenly dawned on me that the underlying cause of it all was Edward.*

**Catherine.** Catherine was a 52-year-old wife and mother of four children. Her child Samantha was a twin born with cerebral palsy; the other twin did not have any disabilities. Her husband was a truck driver and often on the road. Over the years she became physically and financially unable to care for her child anymore after caring for her at home for 22 years. She used a group meeting of family and professionals to make the decision and said it was "unanimously decided." Deferring to the group for the decision seemed to be helpful for her ,although thereafter she dealt with struggles of the placement.

*At the beginning I attempted to be the primary care giver for both children. I very quickly realized that this was an impossible task as I already had a three-year-old daughter at home. This is when I found it necessary to reach out to my family, friends, neighbors, and professionals. I reached out to a family member in Albany who was going through the exact same situation with her daughter. She directed me to the various agencies in Nassau County that handled situations like this. . . . My husband was home and we knew this was the day that we had to discuss placing Samantha in a group home. . . . My oldest child had reached 21 years of age and the twins were 18. Samantha was*

*unable to do anything for herself, she couldn't speak, feed herself, bathe, toilet, etc. She spent the majority of her day in a wheelchair, she was difficult to carry, to move and transfer. She was difficult for us to care for, she was heavy, I was older. It was just very difficult to continue to manage her at home. I had physical issues of my own that I was dealing with. By this time our support system was diminished. Those that were helping us had families of their own, had also aged, and were not able to be supportive. . . . We decided to call a meeting with her doctors, her therapists and our religious advisor. After several hours and meetings of discussing the pros and cons of placement my darling Samantha in a group home was unanimously decided that it would be the best place for her. At first I cried every night, and visited her every day. After several weeks of seeing how she was developing and enjoying her environment I knew then and I know now that it was the correct choice. Before we made this decision we had researched various options and facilities that may have been applicable to her condition, but we found them to be not what we were looking for. . . . In retrospect I know that I would have never been able to provide her the kind of care that she is getting in the group home. I was physically and financially unable to do so.*

**Illyse.** Illyse was a 66-year-old wife and mother of three children. She cared for her son who had autism spectrum disorder for 23 years in the family home. When making the decision for placement into a residential group home, safety was the precipitant. In many aspects the decision was made for the family due to his autistic behavior and a social worker identifying the crisis and need for eventual permanent residential placement through a crisis home. Regardless of the fact that the family “always knew we wanted a place for him” and the difficult at home situation, the family still struggled with the placement reality.

*I couldn't. I could not have done anything differently. I think we just um, went through the very difficult time. We always knew we wanted a place for him. And as heart-wrenching as it was to go through the process, in the end this was our only choice. . . . This was our only choice to keep him safe, to keep us from going insane and to, you know, was worried, and saving the worry and saving the anxiety of how he was going to be in this neighborhood. . . . The decision, it was a decision we, it had to be made. So the fact that it came when it did, we hadn't anticipated it at that stage. . . . We knew it was going to happen down the line someplace but we didn't know when so you know we couldn't have foreseen that it was going to happen as soon as it did. . . . We thought maybe he'd be at least 30 or 40. . . . But then when things got out of control it was okay, we have to do this and this is our opportunity then we have to make the decision and just do it.*

Many caregivers described their readiness to make a placement decision as an ongoing series of adjustments and their realization that PARENTS CANNOT BE CAREGIVERS FOREVER. The increasing physical demands, escalating behaviors of their adult child with ID/DD, their own aging and mortality, the inability to provide the continuous structure and activities to keep their child engaged in meaningful activities, the need and desire for a sense of normalcy in both theirs and their child's life, and the fear at some point in time of the child possibly becoming a burden for a sibling were some of the intervening considerations.

**Emilia.** Emilia was a 71-year-old wife and mother of two children who cared for their child with Down syndrome for 37 years in their family home. The parents had the assistance of a supportive sibling and began planning early for future placement. The mom expressed she could “see the handwriting on the wall” and realized she was getting older and did not want others in the family to care for him.

*I think we were just told that even though it's many years away you got to get on a list. . . . You know, there was this list you had to get on. And, uh, there were, like, 10-page applications for each, um, organization. So we were busy filling out all these applications and submitting them, um, and then as time went on Governor Pataki came out with his we're getting rid of the lists there will be no lists, everyone will be placed. And, um, when that didn't happen. . . . Uh, then they had this, as I said, universal application. And, um, we always worked with a, um, service coordinator from \_\_\_\_\_. Our service coordinator still is through \_\_\_\_\_. And, um, probably which fill out the, the application, the universal one, and submitted it and then we just kind of hung out and waited and, and figured, uh, something will come eventually. . . . And \_\_\_\_\_, I had never even heard of the organization, out of the blue sent us a letter or called us—we had been away and we came home and then we got this, uh, phone call saying that they were interested in doing a meet and greet. So we looked at each other and said, “Oh, he needs to be going there.” . . . Because it was one of those things that you're waiting for, hoping for, and dreading all at the same time. . . . So, I mean, you could see the writing on the wall and as much as it's a very hard thing to do you realize that you're getting older and it has to be done. . . . Because, I mean, we knew that, uh, you know this was what was going to happen. And, uh, then we would talk about it. But what we should have done was have him in respite, you know, overnight and, uh, that we didn't do. But, um, yeah we did, we did talk about it and, uh, it, and it's a good home. . . . Yeah the, making the decision was not hard because we had made the decision. . . . But, um, yeah it was, it was difficult, uh, it was a difficult process. The decision was not difficult the*

*process of placement was difficult. . . . And then, as I said, as we were starting to realize we were getting older, then we thought—and I, I do believe that the, the age was a good age for him. . . . Yeah I, I’m—yeah maybe. If they offered earlier, we probably would have um, taken it.*

**Betty and Raphael.** Betty, a 65-year-old, and Raphael, a 71-year-old, were Laura’s parents who cared for her at their family home for 20 years along with their younger daughter. Laura had Smith-Magenis syndrome. Osorio et al. (2015) described Smith-Magenis syndrome is a distinct and clinically recognizable genetic disorder affecting many parts of the body. It is characterized by mild to moderate intellectual disability, delayed speech and language skills, distinct facial features, sleep disturbances, and oftentimes behavioral problems. Laura’s father Raphael is an attorney, and her mom Betty is well educated with a Master’s degree. The parents expressed that from early on they were aware they were not going to be able to care for their daughter forever in the family home. They began planning for their daughter’s future residential placement early on.

*. . . that you put yourself on the list and you only got to the top of the list when you were 80 and had 1 or both feet in the grave and you couldn’t care for your kid and now you’re 60-year old child is gonna get admitted to the few—to one of the few beds that is available on an emergency basis. So she encouraged us, “Put your name on the list,” and she said to me, “What do you think?” and I said, “Well, I don’t see any harm. There’s no downside because we may never get to the top of this list and if we do and if it turns out that it’s not right they’re not gonna call her a prisoner; we take her back.” And it was to our great surprise that Laura still—was only 20, she still had a year to go in school, and we got a call from the same person who said, “You know one of my jobs is to post—you know after-aging out is placement in residential and day programs and I’m in touch with all of the organizations and when they’re gonna put a new house together they try to group people of similar ability or disability,” and she was approached by \_\_\_\_\_ with plans to put up a new house and she said, “Laura would be a perfect fit. What do you think?” and we said, “Wow, we didn’t expect this but. . . . But we had no idea it was gonna happen so quickly . . . we had planned to care for her until we couldn’t.” . . . Absolutely. There’s somebody upstairs watching us, that’s for sure. So you know that’s why—yeah. I knew all along this is what I wanted to do when I heard about it. . . . You know our biggest fear was that it would be painful . . . it was positive. . . . One of the largest concerns that we had when we realized that she would not be able to take care of herself was who’s gonna take care of her when we can’t and this has answered that question.*

**Jennifer.** Jennifer is a 62-year-old wife, mother of two children, and a registered nurse. Her son Theodore with ID/DD is an adopted child. Theodore is a young man with Asperger's syndrome. Jennifer had a clear vision for the future residential living placement of Theodore and made a 10-year plan to help her child gradually adjust. She ensured that he had a respite worker, a community habilitation worker, and respite weekends. She did not want him to go from living at home without services into a residential group home setting. She expressed that she did not feel it would be good for him to go from nothing to a residential environment. She believed it was important for him to know what it was going to be like for other people to take care of him, and that these types of experiences would aid the transition into residential to be much smoother.

*I accessed a respite worker, um, through \_\_\_\_\_. I really did access every service I could possibly get. . . . And I also knew that my goal for him, um, because Theodore has, you know, multiple issues—um, my neurologist told me a long time ago that Theodore will need some kind of supportive environment. He will never be an independent adult, even though he is very bright. He just has too many organic psychological and neurological issues, so I knew that my goal would be residential eventually. So I didn't feel it would be good to go from nothing to residential. So I did it over the period of 10 years where he had a respite worker, a res hab worker, and respite weekends. And he knew what it was going to be like for other people to take care of him. So the transition into residential was going to be much smoother. So I planned this for a very, very long time . . . but I worked very hard to make sure that I found a place that was going to satisfy his goals and mine. . . . But I think that I found the best that I could have ever found. And he, you know—when I asked him to rate it, 'cause he likes to rate, he gives it a ten, and he tells me that he's been blessed because that's kinda the, the words that we used from the beginning that, you know, "This is not because mom and dad don't want you to live with you anymore. It is really for future." And I also strongly believe that you don't take a disabled individual at the age of 40 or 50 and think that that's gonna work. You need to start at an age where I'm around to help him negotiate the system and get him to understand how it's gonna work so that by the time he's 50 or 40, hopefully, every issue has been resolved. . . . I needed to get him through high school, graduated, into his day-hab, which was another lot of work to make sure I found the right day-hab. Get him transitioned into that situation, and then the next transition was gonna be into the group home, and that's exactly how it worked. . . . Planned years and years and years ago. . . . He has a nurse. He has a house manager. It's not just me anymore . . . honestly as they get older, I think the issues become more difficult personally because they, um, the issues were always there, but as an adult, they have to negotiate the world as an adult which is not an easy thing to begin with. And the more support they can get, the better off they are. . . . And most parents either aren't ready to do the work, aren't ready to make the*

*move, um, don't have the time to do the work. I was lucky enough. I'm not working, so I have the time to do it. It, it's a very difficult situation to, to make, to, to make the decision. Um, it's also very hard to give up control. Um, especially when you're a very, very involved pa-, parent, um, it, it's very different to hand your child over to an agency and now they're in control, but it doesn't really have to be that way if you work as a team. So I think if you put your, your effort in to make it work together, the transition is much easier.*

Jennifer described how in order to be able to make a decision; a parent needs to be “ready.” Being ready, believing in one’s heart it is the correct decision, and supporting one’s decision has a positive influence on how the child will transition, and allows for a successful experience.

*I think that the first thing is the parents have to be ready. If you do this placement and you're not ready, it's not gonna work because you're gonna go in the group home and you're gonna find a million things to complain about, and then you're gonna make the, the adult or child anxious about the decision. You have to be positive about it. That's the first thing, so that the child will be positive about it. You have to believe in your heart that this is the right thing to do. You also have to be realistic that it's not home. You're not the mother anymore. I, I've told Theodore that they're number one now and I'm number two, and he goes, “Really?” . . . I think that you have to think about the future. Parents that don't are making a very, very big mistake. I think the longer you wait, the harder it is.*

**Rita.** Rita is a 57-year-old wife and mother of two children with ID/DD. Her son and daughter were diagnosed with Smith-Lemli-Opitz syndrome. Smith-Lemli-Opitz syndrome is an autosomal recessive syndrome gene mutation that is associated with many congenital anomalies, intellectual impairment, growth delay, behavioral problems, and low levels of plasma cholesterol and elevated sterol precursors (Kelly et al., 2015). She was the primary caregiver of the children with her husband often working out of state. This was a tremendous and exhausting responsibility for her. Placement of the children seemed like the “natural progression” and “only option” for her. The children became too much for her to manage at home, becoming physically and emotionally overwhelming to the point she knew she could not manage anymore.

*You know, Michael did not want to go there in the beginning. I literally physically forced him to go. I had two friends come—because he was just down such a bad—he just had nothing, there was nothing for him and he just was so immature and everything. And I forced him to go there, and um, you know, that’s how I got through in the beginning . . . we couldn’t afford not to do it, there was just no way. I mean he would have killed me or I would have killed him.*

When Rita and her husband were planning for placement, Rita reached out to her family for support. She described her sister as never having children and just incapable of understanding her and her husband’s situation with two children with special needs. Her husband’s family members were out of state and not a resource or support for them either. They relied on friends and other families, many of whom also had children with special needs.

*Well, my husband’s two siblings have been out—you know, out of state for years, so he really has a very limited relationship with them, and my siblings—I don’t know, it’s kinda like if you don’t—well, my sister never had children, so she’s really clueless, and then if you don’t have children with special needs it’s just—I mean how are you gonna—? You know, it’s the same thing, I would talk to my friends about, you know, and Racquel wasn’t too thrilled about going there, so I guess I really looked to my friends, you know, some of them that have—a lot of them have special needs kids. But, you know, your siblings, I mean it’s just—they’re not even in New York. You know, it’s just so different.*

Rita reminded her sister of something their mother had said to them; however, even with the recall of her mother’s words, her sister still did not seem to be able to understand Rita’s and her husband’s predicament. The following dialogue ensued between Rita and her sister:

*Why would you do that? Remember when mommy said—we were, you know, being old-fashioned Italian, you don’t leave the house until you get married. Well, you know what, my kids are probably not gonna get married. What happens when I go and my husband goes, where—then what, you know, but you know what she said, “Well, you have a long time to think about that.” I want to have peace of mind, knowing that my kids—you know, when I hit 65, you know, and my kids are okay, they can manage as far as they can manage. You know, they’re always gonna need support but I want them to be as independent as they can . . . And let me tell ya, I learned from that, you know, I learned from that. They have to realize that you have your own life. They just never did, my kids, never did . . . it came up very suddenly and it was on—it was vacant and that’s when they had, um, the Front Door policy, which just took effect, so everything was like, well, you know, you came up for this but the Front Door, so we have to go through the state. So I thought well, that’s it for that, you know. And then the person who the state came up with went to look at it and they didn’t want it. And then they came back to me and said,*

*“Well, you can go look at it but, oh, did you go through all the”—you know, the, um, you had to go through the meeting for all the Front Door. And so there was all that stuff, and then all of the sudden they said, “Okay, can you have her go next week and stay overnight?” and I said yeah.*

Although the family was confident about their decision for residential placement, they never thought the opportunity would arrive so quickly. They needed to make the decision quickly and did not want to risk missing the opportunity for housing. Racquel’s mom verbalized that she is still trying to figure out many of the logistics of the OPWDD residential housing system.

*Like everything just happened so fast, in like three weeks she was in the place. So it’s not even like I had time to think, all I kept thinking was, well, this is it. And then I spoke to Shelia who is the \_\_\_\_, her case manager, and she said—I remember what she—she said this—I would hate for you to let go of this opportunity, and that opportunity was in my mind, that—because a lot of my friends had said what, are you crazy, you mean you’re thinking about not doing this, and so then I said well, I have to try it. But it didn’t even—I guess I didn’t know really what to ask. I just—and like I said, we had a couple of meetings with the people from \_\_\_\_ but everybody was like kind of—the questions that I had they were very lackadaisical and kinda like oh yeah, that’s not gonna be a problem. So I don’t know, I just kinda jumped in and then kind of—still trying to figure things out.*

**MaryAnn.** MaryAnn is 70-year-old wife and mother of seven children and has a very supportive husband and family. The family, like so many others, made many sacrifices to care for their loved one at home. They had been caring for Marissa for 19½ years at home. Marissa was diagnosed with Rett syndrome, which is a complex neurological disorder resulting from a genetic fault that occurs mostly in females and affects them throughout their lives. Often there is normal early growth and development followed by a decline and slowing of development. In Rett syndrome, behaviors are often autistic-like. Other characteristics include walking on toes, sleep problems, teeth grinding, wide-based gait, hyperventilation, seizure disorders, cognitive disabilities, apnea, and slowed growth. There is no cure for Rett syndrome and treatment



involves treating the symptoms. Life expectancy is generally not expected beyond age 40 (Briggs, 2014).

When Marissa's parents were "ready" to make the decision, they realized that residential placement was the best option for both their daughter and the family's healthy future. Marissa's mother began to experience psychological and emotional symptoms from being the primary caregiver. She realized she "was not built for it." She described the feeling following the placement very poignantly as a feeling of grieving "that is a permanent state of affairs" and that she has realized "it never leaves you."

*So, um, I think as the years went on it just became increasingly clear to me that I couldn't keep up, even though we had nurses and that. My house was like a revolving door, therapists in every day, speech and, um, physical therapists. Sometimes OTs would still come, even though she was going to school, there were lots of services available, and blessedly, we got them all. But at the same time, I had to do—except when the nurse was here four or five hours, pretty basically everything was on me . . . but you know, the mental stress was—I'm just not built for it. I had to finally say you're not built for it. . . . It was a very intense time. Plus, I think I was getting really depressed, really depressed, because I felt like I could not affect any change, even in my life. . . . Especially, more than anybody else's. It was like I'm the linchpin and it's never gonna end. This is gonna be it for the rest of my life and Marissa's life. . . . It feels selfish saying it now but once she did go into residential care, the truth is, when I would go and I'd see 22 people doing what I did, I felt you did the right thing. . . . I remember when I—we told our sons, um, we had already moved—we moved here because the bedroom was on the main floor, a small room, and I would—we would sleep back there and we put the boys up. And then I was right across the hall from her. . . . So I—when we told the boys, I started to cry telling them that we were looking for a place and I think we found one in Yonkers, and I started crying, and they said, "Mom, we think you're doing the right thing."*

MaryAnn was discussing the point in time when she began to discuss the placement with her other children. I asked her to describe how that made her feel, and her response was:

*And they were so young, that really was balm to my soul because I was a wreck. . . . I feel my extended family was supportive. I'm trying to think if anybody felt like—I think everybody felt sad, but on the other hand, I think they felt glad, especially for me and for my husband, 'cause it was a long haul. . . . It just always was so hard. So when she went away I did suffer but more emotionally than physically, which was nice, 'cause I was really shot to bits. I don't want to say that in front of my husband. . . . But I was determined at this point that she really had to move out of this house. She needed*

*someplace that was very regimented. And as I say, it's selfish, I was exhausted, but I felt that—but in retrospect, I don't think there's anything anybody could do. . . . I think when we got there, and they just started feeding her, and I hung around. But you just sort of feel like you wish someone would say well now it's time for you to go . . . you're always grieving, it's a permanent state of affairs. I've really come to realize that, that it never leaves you, you always feel slightly sad. . . . Just slightly sad of the loss, that you couldn't be the one to make her life nice. All the others, I could make nice . . . I could soothe them . . . I could be balm to their wounds. . . . With Marissa, she needed something out of my, uh, expertise . . . you want your child to have everything that child can possibly have including the grief of not having you 24/7, which the longer you wait, I would think, the more difficult it is for the children.*

**Karen.** Karen is a 56-year-old mom of three recently separated from her husband, and currently in a relationship with a boyfriend. She cared for her daughter Kristen for 23 years in the family home. Her daughter was diagnosed with Prader-Willi syndrome and began to have an escalation in her behaviors. The parent caregiver became acutely aware and acknowledged her readiness to make a placement decision based on the realization that she could not go on any longer caring for her daughter.

*Um, I had to say it was always in the back of my mind but never—I never entertained it until I have to say probably her teenage years because I just thought that I would always take care of her. Um, but as time went on and she needed more, you know, really more assistance as far as the eating and, um, her temper tantrums, I knew that eventually, you know, she was probably gonna have to live, you know, in assisted situation. She couldn't stay at home anymore. . . . My family did. My ex-husband did not. He, um, wasn't supportive at all, you know, at first. Um, my children were because at that point they were older so they, they knew that it was the right thing to do because they lived with her. They saw what, you know, what was going on at home. It was actually harder to take care of her when she was an adult than when she was a child . . . actually one of the counselors in high school, you know, brought to my attention, um, placing her in a group home and, you know, just to get started thinking that way. . . . So then that's when it actually started to hit home I would have to say. . . . And what was happening was she was getting worse and worse behavior problems at home and I, I kind of really wasn't planning on doing anything right then and there as far as—I thought maybe a while maybe in 10 years, but it was getting so bad at home that I actually had to call in the, uh, like a crisis line I had to call in. And they're the ones that kind of sent me set in motion to actually apply for, uh, placement because they had to actually remove her from the home at one point because she was not doing well at all. . . . Absolutely I was ready. You know, she was ready and, um, just knew that it was the right thing that I had to do. You know, it's sad, very, very sad in a sense but, um, I was ready for her and happy for her because I figured this was what was gonna, you know, take care of her, be good for*

*her. . . . You realize that, um, it's not that you can't take care of her at home and, um, it's just sad to say that.*

**Edie.** Edie is a 63-year-old wife and mother of three children. She cared for her son Robert for 25 years in the family home. Robert was diagnosed with agenesis of the corpus callosum and autism. This congenital condition is an abnormality of the brain that occurs during the early prenatal period. The corpus callosum does not develop as it should and the condition can occur as an isolated condition or in addition to other physical and medical conditions or other brain abnormalities. It is characterized by a partial or complete absence (agenesis) of an area of the brain that connects the two cerebral hemispheres. The condition can result in subtle developmental and cognitive challenges to more severe disability. Robert suffered intellectually and emotionally from the effects of the corpus callosum agenesis and was also classified on the autism spectrum. The family began to think about residential placement for Robert when he was in high school. After high school, his siblings began to move out of the home; he really had no friends and was becoming very aggressive. The family opted for residential placement. They thought it would be nice for him to have a built in support system and friendship.

*Um, we talked about it a lot when he—I guess when he was in high school, because he really had no friends. He—you know, he was different than everybody and everybody was moving ahead, and he wasn't. So he really had no friends. His brother started moving out, going to college. Um, I think that's when, when they started—when his brother was in college. He—you know, it was just my husband, me, and Robert all the time, and he was—I mean he had, he, he went to programs. He did. But everything was planned and we thought for him, it would be nice for him to have a built-in support system and friendship. . . . The other was he was also becoming very aggressive and yelling and screaming all the time and, you know, we were like puppets on a string. We just didn't know which way to jump or how high, you know, just to keep him quiet. And we thought that moving into a group home would give him more stability.*

The parents had decided it was time because they were getting older and realized PARENTS CANNOT BE CAREGIVERS FOREVER. Their other sons struggled with the parents' decision. They leaned on their faith to guide them.

*I can't take care of him. We're getting older . . . my younger son—it was hard for him, too, but I think he, he could understand more the reason why he—he didn't feel as guilty about it. My other son felt very guilty. He didn't like that we couldn't take care of him. . . . So we discuss it with them. Ultimately, it was our decision. They both realize it was necessary, and, um, also that they wished he was closer. That's the only thing. We all did. But, you know, I'm glad I took the placement because there's not much now. . . . Now what? But we just said, "All right." We prayed about it. We said, "You know what, Lord? If this is the right placement, you know, just help us to step—move forward and open the doors." And that's what happened. We went and it just looked right, you know? The guys looked right. The—it, it just seemed right.*

The family visits him on the weekends. When they come home Sunday evenings, they realize they cannot care for him long term, and although they were “ready” for placement, they still seem to struggle internally with that fact.

*My husband and I, yeah. We come home every Sunday and we like—my husband especially, he's like, you know, it, it's hard. It never gets easy. And it's very hard because we know we can't take care of him. . . . You know? I mean I could take care of him, but it would be—we could take care of him. The thing is, it wouldn't be good quality of life for him, or us, because we would be nervous. We would be anxious all the time, and we'd probably be short with him. And that's not good for him. . . . But I still say, "Did I do the right thing?" I'm asking, "Did do the right thing? Maybe he'd be better off at home." You know? But don't beat yourself up and don't feel guilty that you can't take care of your child. That's the main thing, 'cause that's the biggest thing for parents.*

**Debra.** Debra is a 59-year-old wife and mother of two children. Her son Stanley lived in the family home for 22 years and had been diagnosed with autism spectrum disorder. The percipient to placement was the family feeling exhausted from physically caring for the child. They wanted him in placement when they aged; however, they still struggled with all the issues surrounding a residential group home placement decision. Family and friends assisted them with planning for placement for when the time came that they were ready.

*"Get him on the New York Cares list. Get him on it at 15. You won't have a group home for seven years." I think he was—almost hit it to the nose. He said, "If he, if you cure him, you get him off the list." . . . Jill \_\_\_\_\_ was in on this, too. And she said, "Yes, get him on the list." She said, "It's gonna take years." And I never—I was not ready at—now this gets to the heart of your thing. I was not ready at 15 years old to put him in group home. I was far from ready. And, um, I now advise parents if there's a place at 15, 14, 13, think of it as boarding school, and put 'em in because it's not gonna be*

*anyplace. Take it now. But we didn't have that. I mean it wasn't—we, it wasn't, it wasn't so many. It wasn't the situation.*

The family then reached a saturation point. They were suddenly faced with the reality of exhaustion, recognizing that they could no longer support the needs of their son at home.

*I mean this was, we were really getting tired of it, so we just like farmed it all out, to be perfect honest, 15, 16 after years of being beaten, bitten and you know, he felt worse about it than we did, I know. But, um, everybody was exhausted and, and he was a 15–16-year-old boy doesn't wanna spend his life with his parents. . . . 'Cause my husband was saying, "We're exhausted. We're not gonna make it." He wasn't just saying him, and he was right.*

After Debra and her husband made the decision to place Stanley, she thought she would feel positive about the decision. Instead she was very depressed, although she felt that she and her husband now “have our lives, but I really felt awful” they were still taking Stanley moving out of their home very hard. Friends were saying to her:

*And, and, um, just girlfriends of mine, women friends, you know, people who, other autism mothers who were my really best support. They were saying, "Well, what'd you think? You've been a caretaker. You've been organizing his life from home since—you know for a really 22 years, but for, you know, minus 19 of them with autism. All of a sudden, it all leaves. You think you're gonna feel great right away? No, you're gonna feel awful." . . . Um, the—I felt that, um, I felt depressed, and I felt that there was—you know, I felt I was supposed to be loving this, but there was this—it was just empty. I felt empty. I felt depleted.*

Debra reiterated throughout the interview that it would have assisted her tremendously to have someone help her through the initial decision process as well as follow her through it. She described what she envisions would be helpful with the decision and transition process of placement of an adult child with ID/DD into a residential group home:

*What I felt is that I wanted somebody to alert me to have—I wanted the \_\_\_ to have a group. I wanted the \_\_\_ to really assign me a social worker or somebody who knew this before he went into the group home, when he went, and after, and follow me through the process. Tell me what to expect. Talk to me when it was happening. Talk to me when I thought it should have been over. That's—I, I know I said that, but I want to make that really, really clear.*

Since her decision to place her son, she began to develop a new attitude. She described it as a sense of “entitlement.”

*I always made sure I lived my own life, but now I feel like it’s really important to do that. Like I really—I used to wake up in the morning and say, “What, what will—what will make Debra happy?” ‘Cause that’s what autism mothers do, ‘cause that’s the way you get through the day. But now I really say it in a different way, like, “I’m entitled.”*

**Talia.** Talia is a 54-year-old wife and mother of six children, two of whom are stepchildren. Angela was her fourth, natural child. Angela had been diagnosed with Prader-Willi syndrome with aggressive and sometimes dangerous behaviors. The parents had planned for placement of their daughter by completing the application process. They received a call about an opening in a residential group home setting and at that time were not “ready” to make the decision. They lost the first placement opportunity in that residential home and in hindsight they learned they would never say “no” again. After turning down the one home, the mother had choices of several homes. Her daughter was placed on a highest jeopardy list because she was morbidly obese as a result of the Prader-Willi syndrome and at risk for a catastrophic health crisis.

*I—everybody says it’s gonna take 20 years on a waiting list [laughs], right? So my husband’s bugging me sign her up, sign her up so I’m signing her up and I’m saying. I’m signing her up on all these things and, uh, you know, we’re signing up with every agency, her social worker’s helping us fill out all the things, and, um, we get a phone call a couple years ago that there’s an opening and we should go see it. The social worker takes us. We see it, it’s a nice house, you know, I don’t really remember that too many details about it ‘cause I walked out in my head going I thought I had 20 years [laughs]—I—I’m not ready for this—so, uh, anyway I hemmed and hawed for I would say a good week and a half to two and then somebody who needed it more than her needed it and they got it. I think [crosstalk] if I would have said yes, I’m thinking if I would have said yes and got her right in there I would have secured that placement. Yeah, I really wasn’t ready, I really wasn’t. But I have to say I didn’t think I was ready this time either. . . . Now I understand, I said, because if I had said yes it would have been my choice. Just if I had said yes. I could have said I’ve changed my mind three days later. But by not saying yes I lost it. So then I said to my husband going forward I will never say no. I will never say— will say yes. If they have an opening I’m just gonna say yes, and then we’ll figure it out so I don’t lose it. So we had two or three openings that we looked at, all*

*happened at once—really unusual. So we—we had choices that I don't think very many parents have so we looked at all three programs, she did overnight stays, we picked \_\_\_\_\_, um, only because—not only because, but it seemed a good match. It was about meeting, uh, controlling—eat, uh—everyone in that house has some sort of eating behavior or disorder or whatever. . . . But she's, um, she's still 320 pounds. So the social worker's supervisor wrote a letter, put it in her folder that went out saying that she should be placed at the highest jeopardy list because she's morbidly obese and if things continue, you know. . . . So she got fast tracked and that's why we had the choices.*

This research participant had recently placed her daughter in the residential group home just several months prior to the interview. Talia and her husband continue to deal with the transition and changes in their lives.

*I will say it's I think it's a very positive thing and my husband keeps saying to me like he's reassuring me, um, this is the right thing we're doing. This is the right thing we're doing. He keeps saying it's the right thing we're doing. I said, "Listen, if I had any doubt that this was the right thing I would have already caved and she'd be home." [Laughs]*

Talia's mother-in-law assisted her and her husband to reach the point of personal "readiness." Her mother-in-law had a child with Down syndrome and she had personal experience as a caregiver of an ID/DD adult. She would discuss the need and importance for them to think about the future and residential placement for their daughter.

*. . . the real reason I think, well my mother-in-law had—she lost—she had a Down syndrome that she lost—that was her last child. She lost that child young but she was always involved with—she actually was \_\_\_\_\_. She was one of the original going back like parents that got involved. She kept saying to me, "You can't make your other children take her. It wouldn't be fair. It's not gonna work." She kept—I guess because of her knowledge . . . in the, you know, just as a parent but she saw a lot. She did a lot of volunteer work. She goes, "It'll never work." And she, you know, she kept him—my husband saying—to both of us you're gonna have to put—you better start thinking . . . she was a very compassionate woman—um, kept saying to me you have to—you have to do it.*

Talia expressed how she is feeling after the decision and what she would advise other parents to do in the same predicament.

*I have to almost like detach. I'm not really detached 'cause it's my daughter, and I go down the hall and she's not there and I get a little sick to my stomach, but I think I'm*

*not—I think it’s a mourning to be honest. I think it’s almost a mourning and I think that’s the same thing when they tell you that your child’s handicapped. If it’s not something that you see at birth, which I’m sure makes a parent almost mourn as well, um, a physical handicap or a life-threatening or whatever, but I—I—I think, like you—I got through the she was gonna die and she lived and I was so relieved. Um, but then later when they tell you that they’re handicapped, I think you’re mourning ‘cause you [crosstalk]—it’s not that you lost your child, and you still have this wonderful person, but then you start thinking about all the things they’re not gonna get to do. You know, they’re not gonna go to prom, they’re not gonna have children, they’re not gonna do this, they’re not gonna do that. So I think that’s a mourning and I think this is almost like it ‘cause it’s—it might even be like empty-nest syndrome. You know like going to college.*

With regard to coming to the personal place and point of “readiness” to make the placement decision through her experience, Talia had suggestions and advice for other parents.

*I don’t think I would have put my—I don’t think I would have tortured myself all my life worrying about that—that day that came. I—I mean the hours that I spent worrying and wondering, well if I do put her in a home, well it’s gonna be terrible. She’s gonna think I bet—you know, and maybe, maybe to some degree that’s happening but it’s working. I wish I didn’t put myself through all that for all those years. . . . If I could say to a parent who has a child like mine that’s five years old and say listen, don’t spend the next 20 years worrying about it—because it’s—you’re probably gonna come to this decision, it’s going to work out great, don’t spend 20 years of worry. You know, nothing’s all-consuming but don’t do it.*

### **Readiness: Contrary Case: Parent Decision NOT for Residential Group Home Placement—Research Participant**

**Valerie.** Valerie was an exemplar of a parent who has been caring for her son Joey in the family home for 42 years. At the time of her interview, she had remained opposed to residential group home placement for her adult child with ID/DD. Joey is a 42-year-old diagnosed with moderate ID/DD. He is independent in several areas, and can accomplish activities of daily living with prompting and supervision. Valerie’s story was one of multiple trials and tribulations, yet she remained positive and hopeful. Joey was Valerie’s first-born. She knew early on that “something that was not right with him” and sought services and interventions to assist him to achieve his optimal level of functioning. Valerie had four other children after Joey.



Her husband and “best friend” was tragically killed in a motor vehicle accident when she was pregnant with her fifth (last) child.

She described a period of time in her life surrounding her husband’s death as one filled with multiple losses. Her parents, brother, and her husband all passed away within a one-year period of time that understandably “changed” her forever.

*Maybe that’s why I can’t make a decision about Joey, ever since I lost so many people almost all at once, I am afraid to let go of things. It’s been ever since I experienced so much loss in such a short period of time. Maybe Joey is just something else I don’t want to let go of, maybe that is why and what is keeping me from planning for his future. I just don’t know? I do realize I am getting older, I just turned 67. I need to think about his future, I need to learn more about what is available to him, I need to have a family meeting with my children. It’s hard you know, it’s hard when you don’t have a companion to discuss these things with. I know my children don’t want him in one of those places, they tell me that, yet none have stepped up to the plate to say they would take care of him. Three of my other children still live at home. I know I need to do something, but I am just not ready, I don’t want to let go. In all honesty, the fact of the matter is I really rely on his social security money to help me financially and to help me keep my home. I also just think I can’t let go because of all of the past losses I have had, does that make sense? I don’t know what to do. . . . I can remember it, I said placement? Where would I place my son? My—my thinking like places like for—places like mental institutions, I was like, why would I place my son. I started crying. I was like, this is horrible. Horrible. Why would you even think of such a thing? I—I had no idea anything like this even existed. So I—then she started to—I guess she knew I wasn’t ready. So then she started to educate me.*

Valerie seemed torn on what to do regarding her son’s future. Having him with her in her home is all she knows, although she repeatedly said she needs to sit down with her children and discuss Joey and his future. She seemed to hope that one of her children would agree to take care of him when she is no longer able. She did express that PARENTS CANNOT BE CAREGIVERS FOREVER, but she has not reached the point where she is ready to consider the decision-making process.

Although Valerie has not made a decision for residential group home placement, she, like the other research study participants, struggled with many of the same feelings and concerns

when trying to reach the point of readiness. She has self-identified that she is not “ready” to begin consideration of future placement options for her adult son with ID/DD.

**Core Concept: PARENTS CANNOT BE CAREGIVERS FOREVER**

PARENTS CANNOT BE CAREGIVERS FOREVER was identified as the core concept that was connected to the basic social psychological problem, *caregiver readiness*, to make residential group home placement decisions. The core concept PARENTS CANNOT BE CAREGIVERS FOREVER is defined as the caregiver recognition of the inability to continue to care for their adult child with ID/DD in the family home. The parent caregivers of a child with an intellectual/developmental disability face lifelong challenges that may at some point involve the decision about residential group home placement of the adult child. In the course of the child’s lifetime, the parents who have provided care may need to consider a safe living alternative for their adult child with ID/DD.

In 2015, an estimated 200,000 people with ID/DD live with family caregivers in New York State. Of those people, 50,000 live with caregivers over 60 years old. Unfortunately, the development of new certified residential group homes has decreased drastically since 2008. The need for safe and appropriate housing for this vulnerable population is growing, not shrinking (OPWDD, 2015). Parents of children with ID/DD have self-identified that PARENTS CANNOT BE CAREGIVERS FOREVER.

During data collection, consistent with Grounded Theory methodology, constant comparative analysis with data collection and analysis occurred concurrently. The core concept occurred frequently in the data with other categories related and attached to the main core. The core concept PARENTS CANNOT BE CAREGIVERS FOREVER is the central idea that emerged from the data, and is able to explain variation in the information.

Four supportive concepts/themes surrounded the core concept/central process, PARENTS CANNOT BE CAREGIVERS FOREVER. The surrounding concepts/themes included normalcy for the adult child with ID/DD; the worry and concern that the adult child with ID/DD one day will be a “burden” to other family members; the parent caregivers’ acceptance of their own mortality; and the parent caregivers’ recognition of the need for a support system to assist with early planning and decision making to transition to a residential group home.

#### **Four Theoretical Constructs Attached to the Core Concept**

**Normalcy.** Throughout the research study, the participants spoke about the desire for a sense of normalcy for their adult child with ID/DD. This theoretical construct was derived from prior categories and codes within the data. They wanted their children to be able to experience, as independently as possible, the natural consequences of growing older. Parents expressed how they longed for their children to experience many of the events and milestones, both pleasurable and sometimes not so pleasurable, that their other children without ID/DD experience. The parents were realistic about their expectations, and the degree that their specially-abled adult child may be able to experience these life events. Many spoke about how they wanted the adult child to have a better life than they could provide socially and for their adult child to be with friends of their own age, in some cases with similar abilities.

The longing for a sense of normalcy in the life of the adult child with ID/DD was a consistent desire of the study participants. Parents expressed their desire for the residential group home to be the “new family” for their adult child. They wanted them to celebrate holidays in the group home, to consider the group home a place of their own, a place to call their own, to have friends and even relationships with opposite sex, and to be around people their own age.

Study participant Patricia was discussing with her husband the residential placement of their daughter. She wanted to be sure that the home was the right fit for her daughter's abilities. Patricia did not want her daughter in a home where she would be the one with the optimal functioning level. She feared if that was the case, her daughter would not have a role model. She wanted her to "fall right in the middle of abilities" where people would be learning from her and where she could learn from others. She was more comfortable than her husband in promoting Carla's independence. Patricia shared the following statement:

*She has to have a life.*

Javon, father of Edward, spoke about his son's transition into the home and how the events and occurrences in the home were "normal" to any home, that "this is real life." He described the residential group home as his son's "family" and that is what he wanted for him. He wanted his son to see his housemates and staff as his new "family." Javon was very realistic and understanding about his expectations from the residential setting in which his son was placed. He likened events that transpired in the residential group home to those that can occur in any home. Edward's father realized that placement would provide for these "normal" opportunities.

*I mean you're living in a house! What I would share with you was that as a parent what we would hear when we would talk to the staff in the house is that from our perspective a lot of this is like any other family, and that's what we wanted for him. He's living with his family, for all intents and purposes, not just parents anymore. And that's what we wanted. This is what the real world is about and if he is going to be to the extent that he can be a full and participating member of society and the community and neighborhood that he lives in, then this is what goes on. What we have always felt, and we are on the same wavelength as our close friends is that this is what it should be involved. It's his life. He's got to lead it. . . . If Peter is annoying him, and this would be some of the adjustment problems, hey, you've got to deal with it. I'm not upset. We will get the calls, there was an altercation. Edward got scratched okay, fine that stuff happens, it happens in a regular home.*

Catherine was a mom who had cared for her daughter Samantha, a twin diagnosed with cerebral palsy. From early on, she had wanted and sought out residential placement for her daughter where Samantha would not feel alienated.

*If any mother, father, grandmother, grandfather, family member questioned me about my decision and asked for my advice as to whether they should place their loved one in a residential group home environment, I would say search your heart, talk with your family, and absolutely make the decision to put your family member in an environment where there are people with the same problems and they don't feel alienated. . . . After several weeks of seeing how she was developing and enjoying her environment I knew then and I know now that it was the correct choice. Before we made this decision, we had researched various options and facilities that may have been applicable to her condition.*

Illyse struggled with the process for placement; the decision was difficult for her. She spoke about how it was hard to “release him to the house.” However, her son calls her frequently from the residential group home and they discuss the normal daily events of his life. She saw him moving into the residential group home as a natural progression. She and her husband spoke with Peter, often explaining to him that moving out is a natural and normal progression, that “when you get older you don't live with your parents.”

*But, um, releasing him into the house was, was hard. That was hard. I mean we, of course with the telephone we were on the—we still hear from him two or three times a day. And, um, and it isn't, you know, not—I'm not saying complaining phone calls, they're really not. You know, just telling me what he had for lunch and, you know, how the bus driver was skidding the bus or something. . . . I was thinking more in terms of when people leave home and most people leave home in their late 20s. You know, so he was a little older than that. [Laughter] But, um, and that's what we always said to him, too, you know, your brother got married, uh, he was married 2004, and he had to leave home. You know, and I said, “When I lived at home with my mother and father there came a time where I had to leave home and start my own life and then dad and I got married and I didn't live with my parents anymore. When you get older you don't live with your parents. . . . Well, I mean that's what we experience as the usual progression. And so treating him as everyone else.*

Betty and Raphael were adamant in their beliefs that it is beneficial for “the population to be together” with a sense of “normalcy.”

*I think this decision for residential is so very important because the population should be together so that they can entertain and grow together and not infringe on the other population, which also should have a certain semblance of normalcy and that's a very important factor I think that you should put in there.*

The life Betty and Raphael's daughter could have in the residential group home setting was identified by the parents' readiness and the acceptance of the reality that they "just can't do it anymore like I used to." They recognized that they could no longer provide for her socially or recreationally.

*I do enjoy her but I'm 66 years old now. I can't do it anymore like I used to. We just tire out way too fast. And another thing too is she has a life now that she didn't have . . . \_\_\_ is a great organization and the house is—they have a—she has a very full life. . . . Yeah. I mean they go to the movies, they go to the mall, they go to the Broadway shows, they go to the beach, I mean they go every place. You name it, they go. And she's got, uh—she wants something, uh, they pretty much do it for her. She goes to concerts, um, yeah, the mall . . . yeah goes to the movies. Movies, she sees the first-run movies. The first week they're out they get out and go to the movies. They go food shopping, they go clothes shopping, they go, uh anything you can think of that you and I would do, they do it, going out to lunch, they go to Dave and Buster's; it's, uh—They go to the oyster festival; they go to the arts and crafts fair. And we wouldn't do that anymore. There's a lot of things that we look at and go, I can't do it. . . . But I mean her basic life is still a very happy life and she's got friends, she's got activities, she goes to dances. I never dreamt this was gonna be for her and I was just so grateful.*

The normalcy in the residential setting makes Betty and Raphael happy with their decision. They discussed it with Laura, and explained it to their daughter by comparing it to when her sister left the family home to go off to college.

*They're living normal for their level and they're treated as adults. They can't be treated as when I stand here and go, "I said no and why did I say—because I said so." You know you fall back into that parental—part of it came because her sister went off to college so it turned out to be a perfect time. Hey, you're going off to someplace too. . . . No, as I said, because of Laura going off to college, she thought it was kind of the natural turn of events.*

Betty and Raphael also shared how the residential group home placement provided a "normalcy" for their own relationship, they were able to be "ourselves." When they were no

longer the primary caretakers for their daughter Laura, they were able to become “a normal family unit.”

*I went out to dinner and gee, we were adults not worried about a child. Uh, and friends would call and he'd say, “Sure, we'd love to go,” and we didn't have to worry that could somebody watch her, where was my mother; all of a sudden we were us again and it was something that kind of—you know we liked all of a sudden. We were ourselves. . . . So all of a sudden Laura being cared for, you know we looked at each other and went, “Oh my goodness. We're really free.” So it's—I don't want to sound like, “Oh, we got it,” but, uh, no, it was a whole different attitude. We became, I don't like to use the word, but we became a normal family unit. Children go off to college, children get married, children go and create their own roles and then the normalcy came in and it was a wonderful thing to know and the parents are left behind and they make their roles and that's where you have people getting divorced because I didn't like the spouse in the first place and then like—but in this case yeah, we rediscovered us and why we were all in this in the first place that we had made the right decision. I don't have to worry that when he goes or when I pass on she's in the right place, she's happy.*

Betty and Raphael are pleased that their daughter Laura has embraced her housemates and staff as an extended family. They encourage celebrating events and holidays in the residential group home like a “family.”

*As we get older, you find that the individuals cling together because yeah, they celebrate holidays by themselves because they create it within the house, which is a good thing. You know, they create their own extended family.*

As Jennifer's son Theodore grew older, she came to the realization of what she wanted for him. She wanted him to experience living as a “normal independent adult” and spoke about how important this was to her. In addition, her desire was for him to have a social environment with friends.

*Theodore needed to, um, start to understand what being an independent adult would mean. Obviously, he's not gonna be the independent adult that a mainstream person would be. But, going into group home, he now has chores. He does his laundry. He has to make his lunch. Even though he, he really has a tough time focusing and staying on task, we set up his goals so that he can be as independent as possible. Um, the other things that I think he needs is a social environment. Um, he had a s—he had a somewhat of a social environment with us, but—not the one that he really needs. I mean one friend is one thing. In the group home, he's four other housemates. He has other group homes within the agency that they do things together. It is not healthy to just stay home with*

*mom and dad . . . sometimes you have a single, um, family type of relationship where it's mother and son, or father and daughter, and, and that, that person is your companion. And I think that's a detriment because that person shouldn't be your companion. That person should be out with companions their age. And it's like anything else, I think. You know, they're living a home setting with other people. And when you're interacting with other people, there's always, you know, going to the areas where there's disagreement or there's—misunderstanding.*

Jennifer's desire for normalcy for her son Theodore also included him being an active, participating, and contributing member of society.

*Um, he does have a little part-time job 'cause he's been obsessed with bowling since he's four, so he works at the bowling alley one day a week. That's about all—you know, only for a certain number of hours. That's as much as he can handle, so he does that. Um, she, he's done that since he's 13, actually. So he works a little. He goes to the day-hab. he has group home. He, we have a—he belongs to two different gyms now, with—and, and the group home gets him to the gym. He still is involved with his church. He goes to their respite program twice a month. He still goes to—he used to go to mass every week, he goes to—well, mass once a month 'cause it's a special needs mass.*

Rita wanted her daughter Racquel to have her own friends. Residential group home placement would provide her daughter with an immediate group of peers. Her daughter Racquel often spoke about wanting her own place, wanting to move into her own apartment. Rita and her husband wanted Racquel to live a normal life as an “independent” adult.

*She had a hard time adjusting but she did really well there and she grew a lot, she matured a lot. And when she was back home, I just saw her regressing. I just saw her—you know, getting even shyer than she was. You know, I figured that that's one of the reasons—big reasons to bring her out of her shell a little bit and she did come out of her shell and she had her own friends and stuff, you know, her own life. And then to bring her back here, okay, every couple of weeks I could see, you know, a little regression, a little regression, and I just did not want that. . . . You know, she had—she used to say she wanted to move into her own apartment. . . . Yeah. I want to have peace of mind, knowing that my kids—you know, when I hit 65, you know, and my kids are okay, they can manage as far as they can manage. You know, they're always gonna need support but I want them to be as independent as they can.*

MaryAnn wanted her daughter to be able to go out of the home like her other adult children did. She wanted her to have that sense of normalcy in her adult life. Although



MaryAnn was cognizant that her daughter Marissa did best with a very structured day, she was confident that the residential group home placement could provide her with this.

*And for her, she had a life. . . . And you know and that's a normal progression, where she's a certain age, she goes out of the home like your other children. . . . And—but for Marissa, the best-case scenario is to have a very prescribed day, get up, either go to program or school, come home, have your bath, relax, eat your dinner, listen to some music, interact with the group and—just by being part of it, and then go to bed and then start the same process over again.*

MaryAnn felt strongly about Marissa having her own life and wanted this for her daughter in her adult years. It was important to MaryAnn that Marissa had a social and recreational life that she was not able to provide her due to her own limitations as she aged.

*The child, number one, needs its own life. I mean really, it needs its own support systems. Your family is great, but it's not like where you can go to the football games and support them and go to do this and support them. A lot of parents are a lot more active, too. I just felt like—well, also we were older. I mean I was 45, I think, when I had Marissa. So—and we had been—had all these kids. Some in college.*

MaryAnn is accepting of Marissa's housemates as her daughter's new family. She encourages Marissa to think of her housemates as her family and her siblings.

*It's, like I say, oh, Marissa, how is your family doing, how are your sisters and brothers, where she lives, because basically they're her core group now, and I honor that and I'm very thankful for it. . . . So that's how I would base it, is first of all your child might benefit from having a group of peers.*

Karen wanted Kristen to have her independence, her own group of peers, a place she could call her own. It was important for Karen that Kristen had a sense of normalcy; that when one gets older, one moves on, has one's own place, set of peers, and relationships, and socializes. To Karen's pleasure, her daughter Kristen has even thanked her for helping her transition out of the family home into a residential group home setting.

*When she got placed in the \_\_\_\_\_ home, the group home, then she was fine. Like it was her thing and her place and she liked the other people that were there so she was, she was good and she's good. She's, she's great. . . . They had her go for dinners and meet the other girls there and she loved it. . . . And she was so excited to go so that was the*

*best transition for her. She has a group of peers now, they get older and they move on. . . . Um, she knows like she'll say once in a while that she's glad that I helped her and everybody says the same thing. And they'll even tell her, "You know, your mom did the best thing for you." . . . She wants to go out on her own, though. She wants to live in an apartment and right now she has a fiancé, another young man that is also, um, in the \_\_\_ organization. Um, they're engaged so she's in her mind she's thinking that they're gonna, you know, get an apartment together and get married and all that kind of stuff. So I don't burst her bubble but I don't.*

Eddie and her husband discussed their desire for Robert to have a more independent life.

Robert's parents wanted him to be able to move out of the family home, as his brothers did who do not have a developmental disability. When their other son moved out, they really began to think about residential group home placement for Robert. It was just Robert and his parents in the family home, together all the time. The parents planned everything for Robert yet wanted a different, more independent and normal adult life for him with friends and a support system. The recognition of that PARENTS CANNOT BE CAREGIVERS FOREVER became more obvious to them.

*Um, we talked about it a lot when he—I guess when he was in high school, because he really had no friends. He—you know, he was different than everybody and everybody was moving ahead, and he wasn't. So he really had no friends. His brother started moving out, going to college. Um, I think that's when, when they started—when his brother was in college. He—you know, it was just my husband, me, and Robert all the time, and he was—I mean he had, he, he went to programs. He did. But everything was planned. And we thought for him, it would be nice for him to have a built-in support system and friendship. . . . "You know, you're getting older now. And it, it would be good for you to live on your own, have your own place, like your brother," 'cause his brother moved out at that time, and his other brother was in college. So we were able to use them as an example.*

Eddie only wishes the residential group home that Robert lives in was closer to her home. She could request for him to be moved, but does not want to so do. She said, "That's his home now." She supports other parents advising them to plan for residential group home placement. It is her opinion that parents need to do it, and that it is good for the adult child with ID/DD.

*I think it's good for him to know he has his own life. I think that's a good thing for anybody to feel like they don't have to him be with mommy and daddy all the time.*

Debra was the caregiver for her son with severe autism. Caring for him was extremely challenging and began to affect her health. She and the family were exhausted as Stanley became more aggressive and difficult to manage. They didn't want Stanley to spend his whole life with his parents, as that was not "normal."

*I mean this was, we were really getting tired of it, so we just like farmed it all out, to be perfect honest, 15, 16 after years of being beaten, bitten and you know, he felt worse about it than we did, I know. But, um, everybody was exhausted and, and he was a 15, 16-year-old boy doesn't wanna spend his life with his parents. . . . You know, and I feel like, you know, I, I have things that—I have missions for Stanley.*

The ability for Stanley to have a relationship was important for the family. He had expressed interest in girls and after moving into the residential group home, he became particularly interested in one girl. Stanley's mother encouraged and advocated on Stanley's behalf. She said, "Relationships with the opposite sex are a normal passage for adults."

*Also, you know, something else is that, um, he typed for me that he was interested in this girl. And, and, um, she was not in a group home. She's since moved into one. They had me—you know, first of all, the rules—there are very fair about the rule, which are fine with me. They can do anything they want without mut—I, I used mutual consent. I said, "How are you gonna get it out of him if he doesn't talk?" And I thought it had to be verbal, and I don't know if they're going to accept his, you know, [makes noise] and, um, now they tell—and then I go into the meeting and they say they can do anything up to intercourse without mutual consent. . . . They got them in a room. They sat together. Stanley has a little loveseat couch that he won't let anybody sit on. He has these two big drapes himself over it, and nobody else is allowed on it. He let her sit on it. He sat around for an hour. He usually leaves the room while she was there. She kept saying, "Stanley, Stanley, Stanley, Stanley?" And then one of—one of the guys at the group home—they're like a band of brothers—um, made them take a picture and make—and kinda placed Stanley's arm around her. . . . And, and, and Stanley typed to me, "Mother, don't talk to anybody about this." So, of course, I said, "Stanley, good luck." But, "Don't talk to anybody about this. We are just good friends."*

Debra's decision has left her with great comfort. She feels proud of the accomplishments for both her sons. It brings her peace at how well Stanley is doing since placement into the residential group home.

*I mean it's just the, the—I feel pretty lucky because I—ultimately, I feel lucky because I feel like my two sons are self-actualized, and independent. They're independent people that are living their own lives that, you know, they're, they're not, um, you know—they have jobs. They have work. They have goals. They have friends. And one of them is severely autistic. You know? . . . I mean I didn't cure him. Yeah, you know, I go—I feel awful I didn't cure him. I wake up in the middle of the night, "I didn't cure him." I worry about dying before him, all those things. But I also feel look at how well he's doing. I mean he works on an organic farm. He lives with three guys and they're all over close. The staff love him, because he can be very charming without language. He's just charming. And, um, he—you know, he's like nonverbal alter ego of my other son in the ways people love him. He's charming. He can be difficult. I mean they're, they're really very similar except one talks and one doesn't. You know? [Laughs]*

Talia's daughter Angela was the last of her children to leave the home. As her other children left the home to go to college, she and her husband began to realize quickly that the family home was no longer the appropriate living environment for their daughter. They wanted her to have a sense of normalcy being around people her own age, whom she could socialize with and enjoy recreational activities. The other children in the family home used to interact with Angela, and do activities with her that the parents were unable to complete or "keep up with" any longer. They wanted her to be able to be with people her own age, forming normal friendships and relationships. They wanted her to be treated like everybody else, and have found that the residential group home provides this for her.

*But she didn't have anybody to talk to but us. We're older than her. We're not as much fun as we used to be. You know [laughs]? It's like I'm done. I can't do it. So I—I can't really keep up with a 26-year-old—socially—even a handicap. Yeah, I can't. She needs to go and do with her peers . . . we used to say oh, you're gonna go to college when the other ones were going to college . . . life skills, life skills, life skills, you know, teach her how to do the work, you know, so that when they are on their own in essence they can fend for themselves . . . they did a craft thing. So they went out and got the wood, you know, like the letters of the first name and they all got to decorate them. But I don't do that. You know, I come home from work, I'm tired, I don't do that. So, you know, that*

*alone. They do Zumba. So she [laughs]—she loves to dance. She—I think that’s part of why she’s losing weight . . . I just always wanted her treated like everybody. . . . We’re always gonna worry about her. You always worry about your children . . . handicap, normal, whatever. Wherever they are you’re gonna worry. You put it out of your mind temporarily ‘cause they’re not right under you—you know. It’s like when they go away to college and you don’t know that they’re coming home 4:00 in the morning. So it’s—it’s—it’s kind of really very normal in a very “un” —uh, when you use the word normal, but it is. It just is. . . . But I still think it’s better for her to be with people her own age.*

**Contrary case: Normalcy.** Valerie was pleased with the life she continues to provide her son. Her other children and family members have always considered him just the same as everyone else. She expressed how she made some accommodations for his disability in daily activities when it was necessary. However, she always tries to treat him just as she does her other children and allow him to function at the optimal level he is capable of. Throughout the day, her other children would take Joey with them in whatever they were doing. She has noticed that as her other children are getting older, they are busy with their own lives and do not seem to be as involved in Joey’s life as they were previously. She understands that they have their own families and partners, while at the same time it concerns her for Joey’s well-being. She recognizes that as a 42-year-old man, Joey does not want to “hang out with his mother.” She had been trying to secure a residential-habilitation (res-hab) worker for several hours a week. The assistance of a res-hab worker would maintain the normalcy of socialization. The res-hab worker would be able to take Joey out into the community for activities of recreation and leisure. Res-hab services include the care, skills training, and supervision provided to individuals in a non-institutionalized setting based on the person’s needs. The services can include assistance with acquisition, retention, and improvement of skills related to a variety of activities. These activities can include activities of daily living, personal grooming cleanliness, household chores, food preparation, social, and adaptive skills (OPWDD, 2015).

*Um, by then, I had had the third child. I also had the fourth child, and then when I—my husband was killed, I found out I was pregnant with my fifth child. So and I'm sure all this play—this activity, you know, played a lot in his life. Um, he was just considered part of our family and just a little different, and I tried to not make exceptions for his disability. . . . He doesn't seem to want to spend so much time with me anymore, although what 42-year-old man wants to hang out with his mother anyways? My kids used to be much more involved with their brother, but as they are getting older and have their own families they don't seem to have the time for him like they used to. I want him to continue to be able to socialize, and do activities and recreation. I want him to continue to be involved in the normal things in life appropriate for his age and ability. I have been trying to secure a res-hab worker for 15 hours a week. You know, to get him out into the community, someone close to his age that he can see as a peer. He needs that and deserves it.*

Similar to the families that have made the decision for residential group home placement, Valerie, too, desires for her son to live as normal of a life as possible. She wants him to be given the opportunity to be engaged in recreation and leisure activities with a peer.

**Burden.** At different points in time during the spectrum of caretaking parent, caregivers struggled with the fear of their adult child one day being a burden to a sibling or family member. The parent caregivers had concern that their adult child may be a future burden to a sibling or family member when the parent can no longer care for them. This theoretical construct had an impact on the parent caregivers' readiness to make residential group home placement decisions. The parents themselves identified that PARENTS CANNOT BE CAREGIVERS FOREVER.

Throughout the interviews, there were multiple exemplars from the participants of the theoretical construct of "burden." Parents were concerned that their son or daughter would be a burden to other family members when they were no longer able to care for their adult child with ID/DD.

Patricia realized that if she and her husband did not begin to plan early regarding eventual placement for Carla, she would someday be the responsibility of a sibling. The parents did not want this to occur.

*They need to have a life. And I saw how Carla impacted on our lives, and I did not, I remember back then I was still recovering from all this medical stuff, did not want them to be burdened in their own family lives later on. If I kept her home with me she would be limited in what she was able to do and she would get passed on to a sibling and they would have to worry about her and I didn't think that was fair. So back when she was about five, I figured somewhere down the road she was going to go into a group home.*

Patricia discussed with her husband the possibility of something suddenly happening to the both of them. She did not want to see their daughter Carla with ID/DD be placed with a sibling due to an emergent situation.

*. . . none of her siblings are prepared to take her or able to take her, which they probably would jump up and say they would, but it would be a burden.*

Javon planned ahead for his son Edward. He wanted to ensure that his daughter did not have the future responsibility of caring for Edward in her home, nor the financial burden. He planned ahead regarding placement and setting up a special needs trust.

*We knew that one of the reasons that we were big on getting him into a group home was because we didn't want a lot of burden with the responsibility of day-to-day caring for him because that would just hinder, we felt, her [his daughter] own development and her own ability to get on with what hoped would be a full and productive life. That's one of the big reasons we did it. Not just for Theodore, but for her. Here we are, we did the guardianship, we set up the special needs trust for him so that she wouldn't have a burden. . . . In some cultures family is so strong that, particularly for the, I'll say the poor sister, poor daughter in the family, that's who gets burdened with the responsibility. It's not to my way of thinking, but it's so culturally imbued that, "He's your brother. You have to take care of him. That's your responsibility." It doesn't mean he has to live in your house.*

Illyse knew early on that she wanted to plan ahead for her son's future so that her children would never have to care for Peter on a daily basis. Like many of the other participants, she wanted his siblings to be advocates for him and remain involved in his life, but not on a daily basis.

*We never wanted them to have to take care of Peter on a daily basis so we knew that from early on that we were going to need a home for Peter. That was a really a no-brainer. And uh, we wanted them to have their lives and you know just raise their families—do*

*what they needed to do. And yes to be there for Peter, to advocate for Peter, to oversee his care, fine. Take him home for a holiday, fine, but on a daily basis, no.*

Emilia recognized she was getting older and had the tremendous responsibility of caring for Carmine. She knew her son would be willing to take him, but was also appreciative that he did not fully understand what an enormous commitment the caregiving responsibility of a person with ID/DD was. The identification of this concern assisted her and her husband with being ready to make the placement decision as well as full appreciation that PARENTS CANNOT BE CAREGIVERS FOREVER.

*So, I mean, you could see the writing on the wall and as much as it's a very hard thing to do you realize that you're getting older and it has to be done. And I, I certainly did not want my other son who certainly said, "No I, oh I'll take him." You know. And I said "No you can't do that. It's, uh, there's—you don't understand the responsibility."*

Betty and Raphael wanted Laura's sibling to remain involved in her life. They wanted her sibling to be there for Laura, but not for her to live in her home. They were realistic that one day Laura's sibling may very likely play the role the parents' play, as an advocate, but not to care for her in her home on a daily basis. She wanted them to be able to enjoy each other's company without her feeling the burden of caring for her.

*But I think a lot of that, now here I'm gonna make a mention of this residential part of the thought processing, a lot of it has to do I think because he realizes the organization is going to be stepping first in crisis, in housing, in everything her sister is going to play the role that the parents play, which is I'm back up, I'm supervisory, but I'm not taking Laura into my home and therefore she is not—and I don't like to use the word like this because I don't believe in it—but a burden to her husband or her husband's family and that I think is one of the key factors in looking at the situation of residential. . . . Yeah, because it is. It's one of the main things we realized. I did not want to burden my daughter or her husband or her children with caring for a disabled adult and I wanted her to love her sister and not look at her as a burden. . . . And they enjoy each other's company. They enjoy spending time with each other because it's not a front-line burden situation and that's important . . . she's in the right place, she's happy, and her sister's going to be more than happy to have her for all the holidays and participate but not be a burden to a spouse and not be a burden to her children.*



Jennifer, Theodore's mom, spoke to her daughter about being the back-up guardian for Jennifer's son with ID/DD. They discussed how it would be difficult for her daughter to raise her own family if the situation arose where her brother would have to move into her home. Jennifer and her husband were emotionally assisted in making the placement decision when considering this scenario as one of the potential possibilities in the future. They did not want their daughter to be burdened with this responsibility.

*We talked about it because, you know, I told her that, um, she's obviously the back-up guardian for us, and, um, I know that someday she will take over for us. But we talked about the fact that it would be very difficult for her to raise her family and, and take care of Theodore at the same time. Now would she do it? Yes. Is that the perfect scenario? I don't think so. I don't think it's fair to her, nor is it fair to her family. It's gonna be tough enough for her to keep up the role that I have.*

MaryAnn expressed that the night before her scheduled interview with the researcher, she did a great deal of thinking about what the experience has been having a child with ID/DD. She recalled that when Marissa was 9, she as the caretaker physically felt like she was 90. She thought about what would happen to Marissa if she suddenly was unable to care for her. Her other children were just coming into their own lives and it was her belief that their sister with ID/DD was not their problem.

*I was laying in bed last night and I was thinking, gee, when she was 9, I felt like I was 90. I kept thinking, we have to do something, suppose I die, what's gonna happen to her? Michael has to work. I mean what is—he can't take off. My children are all on the cusp of becoming, they can't—it's not their problem so to speak.*

Karen's situation became increasingly difficult in the home with her daughter Kristen with ID/DD. She was going through a divorce and the situation was becoming extremely stressful caring for her daughter. She explained how it was not her other children's place to assume responsibility for their sister. She took everyone into consideration when making choices and decisions.

*You know, years ago they would say, "Oh, my goodness, you know, you can't do that. It's your child. You have to—" But I'm a firm believer that when you can't solve something in the home and you have to look for outside assistance, that's what you have to do. You have to do what's best for the person that needs that help. Just like, you know, whether it's a nursing home, which is a horrible thing to even have to go through, but that's what I felt with Kristen. I felt that I tried my best to do whatever I could do, and if I get sick, then what? Then what happens to her really? You know, it's really not good so that's what – you know, I wasn't being selfish. Yes, it was gonna help me also because my life was very stressful with her home, but I just felt it was the right thing for everyone. I took everyone into concern.*

Eddie and her husband's not wanting the siblings to be the caretakers of their brother Robert impacted their placement decision readiness. One of the children felt very guilty about the placement. He did not like the fact that they could not take care of his sibling anymore.

*My one son—it was hard for him, too, but I think he, he could understand more the reason why he—he didn't feel as guilty about it. My other son felt very guilty. He didn't like that we couldn't take care of him. But, you know, as we explained to him, "Son, you know, we do not want you and your brother to have to take care of Robert all his life. You have a life, and I want you to be his brother and always be there for him, but I don't you to be his caretaker. It's not fair." I don't think it is. We—my husband and I don't feel that that's what we want. We don't want our children to be a ch—their brother's caretaker. . . . He gets it, but he feels guilty I think. He wants to be able to take care of his brother, but I said, "You take care of your own family. I'll take care of him."*

Talia discussed how it became very apparent to her that it is not her children's responsibility to raise their sister Angela. Talia worried about Angela having the potential to become aggressive toward a grandchild. This realization assisted her and her husband with being ready for a placement decision. In addition, her mother-in-law who raised a child with Down syndrome continuously told Talia and her husband, "You can't expect your other children to care for her. Start thinking about future placement."

*So, um, it—it—anyway, it became very apparent that it really isn't my children's responsibility to raise their sister and to have her live with them. And I don't think that would be good either because they can't take her and do, and when they have their own children I don't even know, you know, if she blew a fit like the pillow pet and there's a little one. . . . Well, my mother-in-law had—she lost—she had a Down syndrome that she lost—that was her last child. She lost that child young but she was always involved with—she actually was \_\_\_\_\_. She was one of the original going back like parents that*

*got involved. She kept saying to me, "You can't make your other children take her. It wouldn't be fair. It's not gonna work." She kept—I guess because of her knowledge—in the, you know, just as a parent but she saw a lot. She did a lot of volunteer work. She goes, "It'll never work." And she, you know, she kept him—my husband saying—to both of us you're gonna have to put—you better start thinking.*

The theoretical concept of parent caregivers' concern that their adult child with ID/DD would potentially be a burden to a sibling/family member when they could no longer care for them was one of the precipitants to the identification that PARENTS CANNOT BE CAREGIVERS FOREVER while making residential group home placement decision.

The identification of this theoretical concept and the caregivers' response to it were purposeful or deliberate acts taken to resolve the basic social problem of parent caregiver readiness. All actions were linked to the core concept PARENTS CANNOT BE CAREGIVERS FOREVER.

**Contrary case: Burden.** Atypical of what all the other study participants expressed, Valerie is hoping that one of her other children will offer to care for Joey in their homes when she is no longer able. Valerie's children have had conversations with her multiple times about the fact that they do not want him to be placed in a residential group home, yet none of them have come out and said they would assume the responsibility. Conversely, the other study participants who already placed their adult child in a residential group home were all concerned about the potential of their adult child with ID/DD eventually being the responsibility of a sibling. They did not want this to occur and had recognized the need for proactive planning for the future so that a sibling would not be burdened with the day-to-day caregiving responsibility of their sibling with ID/DD.

*You know, his brothers and sister are always telling me, "He's not going to a group home, why would you ever do that, he doesn't belong there, he should be with his family." Although they keep saying that, none have stepped up to the plate yet and offered to be his caretaker. Don't get me wrong, they help me here in the home and I*

*couldn't do it without them, but what happens when they move out, or when I just can't do it anymore? What is going to happen to Joey? I just don't know, I don't know. I have to plan that sit down with my kids, this conversation must be had, that I know. Deep inside I am hoping that one of them agrees to take care of him, that they tell me, "Don't worry about it, I'll take him." I am just not so sure that will be the case anymore. They are busy with their own lives and families. I just don't know what to do. I have to really start thinking about it; you know, I'm 67 years old. Oddly enough, I was thinking last night about our meeting today, and trying to get my thoughts in order to participate in this interview. It was really a wake-up call for me. It suddenly dawned on me that I should be making some moves in the direction for Joey's future. You know it's just so hard when you don't have a partner to discuss these things with, it's just so hard.*

Valerie expressed that she was hoping one of her children would assume the caregiving responsibility for her adult son with ID/DD. It seemed as she talked about it "out loud" during our interview that she was coming to her own realization this might not happen. As she spoke about her current situation, it was as if she began to recognize her other children have their own lives and responsibilities, and may not be able to assume the care of their brother with disabilities.

**Mortality.** The theoretical concept of the parent caregivers recognizing their own mortality was a critical factor in being ready to make a placement decision and face that PARENTS CANNOT BE CAREGIVERS FOREVER. This came through the acceptance of their own mortality and the reality that they will most likely not be alive for the duration of the life of the adult child with ID/DD. Many parents expressed the realization that some of their own health conditions were directly related to the physical and mental stresses associated with caring for their adult child with ID/DD. Naturally the adult child with ID/DD was unaware of how their often-progressive physical disabilities, cognitive decline, or increase in aggressive behaviors were impacting the parents.

Patricia was more realistic than her husband. She was aware that something could happen to the both of them at any time, and then thought about what would happen to their

daughter Carla. She did not want Carla's siblings to be responsible for their sister. Patricia feared the potential necessity for possible future emergency placement, and was knowledgeable about how the OPWDD residential system operated. She worked as a nurse in the ID/DD field. She knew that she and her husband could not be caregivers forever and was ready to make the placement decision.

*Did he want to put his daughter in a place like that? Not really. But he could go along with it. I think the most important thing that I brought up to him was if something happened to us and we're all getting older, you never know, say you got run over by a car tomorrow and we're dead, and none of her siblings are prepared to take her or able to take her, which they probably would jump up and say they would, but it would be a burden. But say they weren't able to and then you're going to look at emergency placement. I said, "Honey, nobody should have to deal with that. It is so hard; they get uprooted out of their home, they've lost their parents, there's no way to ease them into the situation, they don't get a choice of where you're going, you get the open slot, the people in the house might not be compatible. Don't do that. Don't ever put somebody through that." We have the opportunity to not have that happen, to ease her into this and make it good for her. And that's what we need to do for our daughter. And that's what we did, the decision became obvious and necessary.*

Illyse was very stressed emotionally and physically with caring for her son Peter. As Peter was getting older, he was becoming more difficult for her to manage as she too aged. She worried about what would happen to Peter when something happened to her and to her husband. They did not want his siblings to be the caretakers. Rather, they wanted their other children to be able to oversee and only help.

*He's nonverbal, he's this. I'm tired, I'm exhausted. I'm getting older. I need to have a plan. And that was always a concern for my husband and me because we were older. I was 38 when I had Peter as compared to being 23 when I had my first two. You know and then it's like oh my goodness, before we turn around my husband's 70 now and I'm gonna be 66 in a couple of weeks and it's like you know what, we just got very lucky that we got a placement for him. . . . The decision, it was a decision we, it had to be made. . . . Going forward, you know if something were to happen to us that our kids will be able to oversee and help and that's it.*

Emilia and her husband faced the difficult thought of something happening to them while Carmine was still here. They realized they were getting older and needed to think about the

future. It was important to them to make the placement decision while they were healthy and able to watch and advocate for him when he was in the residential group home setting.

*I mean, well, in, in terms of health, thank God we are both pretty healthy and so health didn't have to enter in to it. But, but the thoughts of something happening while he was still here was difficult to, to think about, you know. . . . And then, as I said, as we were starting to realize we were getting older, then we thought—and I, I do believe that the, the age was a good age for him. . . . Well, we're here, we're here to advocate, that's why we're putting him in while we're here and healthy so that we can watch and, and advocate for him. And I felt, I felt he would be safe. I didn't really worry about that.*

Betty and Raphael were very realistic about their own mortality. They wanted to be proactive in placement planning for their daughter. They realized that she would be unable to care for herself, and knew PARENTS CANNOT BE CAREGIVERS FOREVER due to their own eventual passing most likely before their daughter. This, in addition to not wanting their other daughter to have to care for her, prompted their readiness regarding placement decision. Their question of who is going to take care of their daughter when they cannot has been answered.

*But you know, we're not gonna be here forever so it's gonna have to fall on someone . . . what happens to that child after we're all gone? . . . You know, I wish I could live forever and take care of Laura and not have her as a burden to even the state, but I can't do it; it's unrealistic. And we didn't want her sister to be on the front lines of that because it'll ruin her life—not ruin her life, it'll alter her life not the way she wanted. . . . I do enjoy her but I'm 66 years old now. I can't do it anymore like I used to. We just tire out way too fast. And another thing too is she has a life now that she didn't have . . . I don't have to worry that when he goes or when I pass on she's in the right place, she's happy, and her sister's going to be more than happy to have her for all the holidays and participate but not be a burden to a spouse and not be a burden to her children. . . . One of the largest concerns that we had when we realized that she would not be able to take care of herself was who's gonna take care of her when we can't and this has answered that question.*

Jennifer and her husband spoke to their son Theodore about the fact they would be unable to care for him forever. They agreed to a mutual “contract” of what criteria had to be met

regarding the residential placement. The requests Theodore had matched the same requests the parents wanted from the residential group home setting.

*We told him slowly that, um, mom and dad are not gonna be here forever, that we felt that he—actually, what he told us is we had to satisfy five things. So we had a very open relationship. It had to be a house in a decent neighborhood. It had to be a house near to where I live. He had to have his own room. He had to have housemates that were, um, not—that were—how did he put it—that were going to respect him and they weren't going to be behavioral, and he was gonna have nice workers. And I told him that if I could find those five things, that that's where—that's when he would go. And he agreed to that contract and we found it. . . . So I knew what I wanted. They were really the same requests that he had, but I worked very hard to make sure that I found a place that was going to satisfy his goals and mine.*

Jennifer expressed her personal belief regarding residential placement of an adult child with ID/DD as not saying goodbye. It is her opinion that parents need to work with the group home to ensure that when they are gone, their child is comfortable, happy, and as independent as possible within the group home life.

*So I have no regrets. It's working. I can't say that it's not work on my part, because it is. I don't think that you put a child in a group home and say, "Goodbye." I think that's a mistake. I think you need to work together to make it work so that someday when I'm not on this earth, hopefully, he will be comfortable and happy and be more independent with his decisions and not depend on me so much. That's my goal for him at this point.*

Theodore's mom shared her fear of if something happened to her and he had to have emergency placement, where would he end up being placed? She wanted to ensure she was able to select his residential group home setting and was ready to do so when accepting her own mortality and the fact that PARENTS CANNOT BE CAREGIVERS FOREVER.

*My fear was, [clears throat] something happens to me and he's placed somewhere, Lord knows where, in an agency that I, I'm not familiar with. How is that ever gonna work? So I knew to be the one to pick the agency, to pick the place, to pick the room, to pick, to pick everything, to know that at least I did my part so that they can take over their part. . . . And I'm not gonna say that it was an easy decision because sure, I would love to be in control and be his mom and his caretaker for the rest of our—his, his life, but I know that that's not realistic.*

Rita spoke with her sister about her own mortality and worried about what was going to happen to her two children with ID/DD when she and her husband were gone. She was ready to have the peace of mind that came with the residential placement decision. She knew PARENTS CANNOT BE CAREGIVERS FOREVER and wanted to assist her children in living as independent lives as possible when she was no longer caring for them.

*What happens when I go, and my husband goes, where, then what, yeah, being realistic about things . . . Yeah. I want to have peace of mind, knowing that my kids—you know, when I hit 65, you know, and my kids are okay, they can manage as far as they can manage. You know, they're always gonna need support but I want them to be as independent as they can.*

Mary Ann discussed how difficult it was caring for her daughter and physically breaking her down. She realized that she needed to plan for the future and was ready to consider residential group home placement. She did not want her daughter to become her other children's responsibility should something happen to her and her husband. She wanted her daughter to experience what it was like to not have her parents 24 hours a day, 7 days a week.

*I was laying in bed last night and I was thinking, gee, when she was 9, I felt like I was 90. I kept thinking, we have to do something, suppose I die, what's gonna happen to her. Michael has to work. I mean what is—he can't take off. My children are all on the cusp of becoming, they can't—it's not their problem so to speak. . . . The other aspect is, you are not gonna live forever, that's a sad thing to say to people but you want your child to have everything that child can possibly have including the grief of not having you 24/7, which the longer you wait, I would think, the more difficult it is for the children.*

Mary Ann was appreciative of how difficult it is today to secure a residential group home placement and realized she needed to begin exploring options.

*. . . and even thought right at this moment it might not seem like the same thing, but you need to think down the line at 12, 8, 6, 15, none of us know how long we're gonna be around, and to have your child in a secure environment which is very difficult to access today.*

Karen was a single parent of three children going through a divorce. Her daughter Kristen became more and more difficult for Karen to care for at home. Karen began to think



about her own mortality and what would become of Kristen if something happened to her. Like so many of the other parent participants of this study, she did not want her children to end up having to care for their sibling. She acknowledged that PARENTS CANNOT BE CAREGIVERS FOREVER. She embraced and accepted the readiness for placement decision.

*Um, I had to say it was always in the back of my mind but never—I never entertained it until I have to say probably her teenage years because I just thought that I would always take care of her. Um, but as time went on and she needed more, you know, really more assistance as far as the eating and, um, her temper tantrums, I knew that eventually, you know, she was probably gonna have to live, you know, in assisted situation. She couldn't stay at home anymore. Um, it's terrible to say but with my other two children also, I didn't feel that if anything happened to me that I would want them to be responsible, you know? I wanted—I really wanted her to have her own thing more or less so . . . and plus I was going through a divorce so that, that didn't help either.*

Karen shared her struggles with the decision-making process and when one is unable to solve something in the home, one must look for outside assistance. She thought about what would happen if she were to become sick and tried to take everyone into concern with the placement decision process.

*You have to do what's best for the person that needs that help. Just like, you know, whether it's a nursing home, which is a horrible thing to even have to go through, but that's what I felt with Kristen. I felt that I tried my best to do whatever I could do, and if I get sick, then what? Then what happens to her really? You know, it's really not good so that's what—you know, I wasn't being selfish. Yes, it was gonna help me also because my life was very stressful with her home, but I just felt it was the right thing for everyone. I took everyone into concern.*

Eddie and her husband wanted to plan for a safe environment for Robert, recognizing that they will not be here forever to care for him. They were ready to make the decision for the placement of their son Robert in a residential group home. One of her sons wants to be able to care for his brother. She believes this is unrealistic and that he does not fully understand the commitment and responsibility involved in the day-to-day responsibilities of caring for an adult

with ID/DD. She informed her son that his brother is staying in placement and what he chooses to do when she is gone is his decision.

*I can't take care of him. We're getting older. . . . He really doesn't have the choice to stay here forever. We're gonna die eventually, so eventually he's gotta go somewhere. So we need to have him in a safe environment before that happens. . . . My son wants to be able to take care of his brother, but I said, "You take care of your own family. I'll take care of him. When I'm gone, you can take care of him," you know? And, you know, "And then whatever you do when I'm gone, that's your business. But right now, he's staying in the placement."*

Debra had been caring for her son with severe autism for many years. She discussed the fears experienced by many parent caregivers. She and her husband recognized the reality that they will most likely not outlive their child with ID/DD. This participant was also an author and shared the experience of friend who was a mother. She wrote about this mother who struggled with the concern of her passing before her child and the fear of what would happen to the child. The mother shared with Debra that she would let her child live until 75 and then kill the child and take her own life. Debra too shares these fears, but also recognizes how well her son is doing since she and her husband made the decision for residential group home placement.

*I've heard other parents say is that how can I live to 100, you know, so that—and I—and, and how maybe—you know, I—I've written this in my novel, um, and when I read it, people cry, but then I have a mother with a very severely autistic kid who says, "I'll make a deal with you that, um, what if you live till 75 and I live to 100?" I mean the age difference is different. "And I'm going to, um, kill you when you're 75, and then I'll kill myself the next day." 'Cause none of us parents want to, you know, want our kids—we're afraid if we die, what's gonna happen. . . . I wake up in the middle of the night, "I didn't cure him." I worry about dying before him, all those things. But I also feel, look at how well he's doing.*

Talia was a parent caregiver who had recently made the decision for residential group home placement. At the time of the interview, her daughter Angela had been residing in the group home for only two months. Her sense of readiness occurred when she realized that PARENTS CANNOT BE CAREGIVERS FOREVER and the likelihood that they will pass

away before their daughter. She described the acceptance of one's mortality as the driving force for parents of children with ID/DD for readiness for residential group home placement decision-making.

*I mean I'm only two months into it so I'm no expert but it has to be done. That's how I feel. I did not feel that way when she was younger. I—my plan was she was gonna live with me till the day I died and then she was going with one of the family members, but that's not really realistic. . . . But to me again the reason for my decision was because some day I'm gonna die. I'm older than her, so odds are I'm gonna die before her. I die before her, she loses—or me and my husband. You know. She loses her house, she loses her caretaker. . . . So, um, it—it was always about what's gonna happen to her later. So that is I think the driving force for probably most parents. As long as somebody's willing to admit they're gonna die. You know, and—well, when I was younger I was like, well, I'm not gonna die for a long time. I'm not doing that, you know? But as soon as you—you have to admit to yourself you are gonna die and what happens then? So it all has to be about death.*

In summary, the theoretical concept of mortality was a common thread throughout the data. The parents indicated it was best to place while they themselves were still healthy and capable of advocating and making decisions. They were reassured that placement was not saying goodbye and they would remain in the life of their adult child. By deciding on placement, parents knew they would be assisting the siblings of the adult child with ID/DD to be able to maintain a healthy relationship with each other. It was identified that once parents accept and embrace their own mortality, it enables them to accept the realization that PARENTS CANNOT BE CAREGIVERS FOREVER and helped propel them to a necessary point of placement decision readiness.

**Contrary case: Mortality.** Less than a year ago, Valerie experienced her own health challenges. She was taken to the hospital with acute chest pain requiring immediate surgery for a cardiac stent placement. She said this was the first time she ever was forced to think about what would happen to Joey if she suddenly was gone, and it scared her. Although she as the primary caretaker experienced this life-changing event, she still finds it difficult to really think

about this reality. She wants to have conversation with her children and in many ways is fearful of their reaction and potential responses.

*You know, Laura, I am realistic and understand that I am not going to be here forever. I can't say that I had been thinking about it until an event last year. You know, last year I had the scare of my life. I was here at work and began having horrific chest pain. I went to one of the other nurses and told her what I was experiencing. They call 911 and there I went out in the ambulance to the hospital. Everything following was just a whirlwind and before I knew it I was having emergency stent placement. Wow, did that scare me. I kept thinking about Joey, what's going to happen to him if I die, where will he go, will his brothers or sister take him in and care for him. All these things were rushing through my head. Talk about shaking some reality into me; that did it for sure. But even so, I still haven't made plans for Joey. I have tried talking to the service coordinator for some advice. She's a young kid, just a kid herself, younger than my youngest daughter. Don't get me wrong, she really tries, but I don't think she has the experience. I don't think she has all the information, or should I say, all the correct information. I know I need to talk to someone and at least learn what's out there as far as options. You know, what my options are. Do you know anyone I can talk with?*

Similar to the other study participants, Valerie has come to terms with her own mortality.

Although the other study participants self-identified and accepted this early in their lives, for Valerie it was different. This almost seemed to be a forced revelation for Valerie when she experienced her own health crisis less than a year ago and was faced with her own mortality. Nonetheless, it has started her thinking about the need for future planning, accepting the fact that PARENTS CANNOT BE CAREGIVERS FOREVER. She recognized the necessity to explore options and plan ahead for the future care of her son. Valerie expressed that perhaps it could be a family member who will provide care for him. However, she also stated that perhaps it might be another type of caregiving situation. The study participant asked this researcher for some guidance and the researcher put her in contact with a family support/advocacy group.

**Support system.** The parent caregivers acknowledged many factors when considering residential group home placement. Impacting on their decision was the presence or lack of presence of an adequate support system in many areas including the healthcare team, other

parents, support groups, family members, or friends. Many expressed the need for and found guidance and support helpful during this difficult decision-making process. Several parents reported they had the support of family and friends, while others reported a lack of understanding from family members of the caregiver's situation. Many of the participants expressed they did not receive information from the interdisciplinary team regarding early planning and possible future residential placement for their adult child with ID/DD. Others expressed the desire for a shared decision-making process from members of the healthcare team with information, guidance, and resources provided to them so they could feel informed and confident with their decision process. Parents expressed this information sharing would have assisted them with early planning and aid in the transition process for their adult child with ID/DD.

Patricia spoke about basic things that a parent needs to know when transitioning their child into a residential setting. In her experience, she believed that if parents were given this information prior, much of the early discord in the residential setting could have been avoided.

*There are certain things that you really need to know to make the transition easier, not that it will ever be easy. Their expectations were unrealistic and due to that in the beginning for the first 18 months at least, there was a lot of discord in the house. Staff were quitting because of the altercations with the parents, and the parents' interference. And that all could have been avoided had they been presented with a realistic view of what was going to transpire. . . . I recommend you do something like that at your site at least SIX months in advance.*

Patricia said she and her husband were not afforded any type of support group. She saw this as something very valuable in helping parents with their readiness to make the placement decision. She felt ill prepared on the basics, such as what to send with her daughter, what the daily agenda would look like, who will oversee the medical care, and meeting the healthcare team in advance. It was her opinion that if all of these logistics were addressed early on with

parents, it would allow them to “speak from their heart” and support each other through the transition process.

*I would think of it more as a support group. That in the beginning optimally it should be the family of the individual moving in with the other family so that the other individuals moving into the house; small group. You're getting to know each other right away. Maybe the first session you talk about who you are and your kids and la-la-la. After that you need to meet with a Residential Director and get a schedule of what actually happens in the house and what the expectations are. And you need to meet with the manager, sit down and talk about how is this transitioning going to work? Believe it or not, we didn't even know what we were supposed to supply. Linens and stuff like that, the basic stuff and what's going to be in the house. And when they're in the house, what is the agenda going to be? What are they going to be doing on what days and how is that going to do? And who is going to be doing the cooking? They need to meet the nurse. Who is going to be running the appointments? Who is going to oversee the medical care? None of that was done. Who is cleaning the house? Who's cutting the grass? After you get the basics that everybody really has to know, then having the families actually; they'll know each other better and be able to speak from their heart about their concerns and support one other through this transition.*

Patricia spoke about what she envisioned for families transitioning their adult children into a residential group home. A support group is what she believed would have helped her and her husband with the process. In addition, a support group could have provided an opportunity for parents to get to know one another.

*To be able to support one another through that would have been a godsend, but yet those relationships hadn't been established.*

Patricia saw other parents who were struggling with the transitioning of their child moving into a residential group home. When the adult child with ID/DD was having a difficult time adjusting to the residential group home setting, the frustration, emotions, and struggle trickled down to the parents as well. It is her opinion that parents could benefit from short-term counseling.

*Short-term counseling for parents when they have a child and are having difficulty making a transition.*

Javon was very methodical in his planning for the transition of his son Edward. He encourages other parents to do the same, be involved, and support one another. He said to make contacts and continue information gathering. Javon likened the role of a parent to “networking for a job” and that the relationships developed are crucial in aiding with the successful transition of the adult child with ID/DD into a residential group home.

*And it's certainly unique for those who are charged with the responsibility, often the parents. There may be any number of things that might be helpful to them. Sometimes it's a question of have you been in touch with an attorney, so that you can properly plan for things that are going to take place in the future? How are you going to protect his entitlements or sure that he is going to be able to receive the entitlements under Medicaid or whatever source and that might be the source of information that they're seeking. . . . It's like networking for a job, people just looking to find the right way into the door and then after that they've got to do it on their own. . . . That's what it's been for my wife and I. It's a relationship. That's what it is. It's a way of, from my perspective just giving back.*

Javon expressed that he and his wife “instinctually” knew what to do in navigating the system. However, he has met many parents who did not know where to begin once they were ready to make the placement decision. He was a proponent of support groups for parents and encouraged them to be their own advocates for their adult child. It is important for the parents to realize they are not alone, there are other people going through the same situation. Parents need to be reassured that there are people who can assist.

*People say, “How do you and your wife do this? How do you manage it?” And our response has always been, “We don't know any other way.” I don't know how I knew. It brings tears to my eyes. I just do it. And then you have to put that into perspective that there are a whole bunch of other people that don't know how to do it. It's not instinctual to them. Whatever their circumstances are, they don't know how to deal with it. They're less educated. They've grown up in a different environment. . . . There's so many factors. There are a lot of people out there who need help. If I can help them in some small way getting them to an organization like \_\_\_\_\_, as difficult as it is in the current environment to get anything done. Just reassuring them that there are supports. They have to be their own advocates and advocates for the individual. They may not have heard this stuff. . . . And like a lot of things, they're not alone. . . . Other people are dealing with it, other people have dealt successfully with it. Everybody's different. There are people out there to help you. It's like a 12-step program. Part of that is what it is.*

*It's not that you have a problem, but you have a situation. And the first thing is, get a grip on it. This is what you're dealt with. Some people choose just to give it up. There's divorces, this and that and the other thing. They don't know how to cope with it, or they're incapable of coping with it. It's unfortunate. For those that at least ask, there's solutions out there. It's like the support group when you have an illness or something. Sort of the same thing.*

As Catherine's daughter was getting older, she became more difficult for the parents to care for. Her support system had begun to diminish, as those who had been assisting were unable to continue to be as supportive. They had their own families and health difficulties, and were getting older.

*My oldest child had reached 21 years of age and the twins were 18. Samantha was unable to do anything for herself, she couldn't speak, feed herself, bathe, toilet, et cetera. She spent the majority of her day in a wheelchair, she was difficult to carry, to move and transfer. She was difficult for us to care for, she was heavy, I was older. It was just very difficult to continue to manage her at home. I had physical issues of my own that I was dealing with. By this time our support system was diminished. Those that were helping us had families of their own, had also aged, and were not able to be supportive.*

Catherine realized early on that her twin daughter Samantha would require residential group home placement. When she was ready to make a placement decision, the mere fact that she was "ready" was not all she required to move forward. It was important that she had an understanding of the resources available to families. She fortunately had a friend in Albany, New York, who had a daughter in a similar situation and was able to guide and assist her. This information provided her a starting point in the OPWDD system and a blueprint on how to proceed.

*At the beginning I attempted to be the primary caregiver for both children. I very quickly realized that this was an impossible task as I already had a 3-year-old daughter at home. This is when I found it necessary to reach out to my family, friends, neighbors, and professionals. I reached out to a family member in Albany who was going through the exact same situation with her daughter. She directed me to the various agencies in Nassau County that handled situations like this.*



Catherine had suggestions for members of the healthcare team and how they could be supportive to families faced with this decision-making process.

*Healthcare members can participate with the parents early on when they are aware there is a developmental problem with the child. Perhaps they could direct the family to the correct organizations, facilities, and providers. Help to connect families with other families of children with disabilities. In my opinion, they are an invaluable resource in sharing the many problems that face the people that have to make this very difficult decision.*

Illyse cared for her son Peter, who had autism, for many years. She had the support of her husband, and housekeeper; however, the readiness for decision placement decision occurred when she feared for her son's safety. Peter eloped from the family home on multiple occasions in a neighborhood with high-traffic volume. In order for anything to occur with group home placement, she realized that it was important to begin "networking" and advocating.

Some parents she knew wanted to start their own home for their children with ID/DD, but they quickly realized the importance of having an agency to provide the necessary services.

*"You have to go to meetings. You have to network. You have to talk to people." I said, "That's the way to do it." I said, "If you stay home nothing's going to happen." I said, "You're gonna have to get out there, go to the meetings, talk to people, let them know what you need and find out you know who you need to talk to and you have to get lucky." . . . I know parents are trying—they wish they could set up their own homes. I said, "You know we're four families. You want to do this on our own, that's in the end you need an agency to provide the services."*

Illyse expressed that the members of the healthcare system could help support families by reassuring them. She said the reassurance from the interdisciplinary team is "crucial to success in the transition process."

*To help other people, if other families came to them and if you could reassure them that they are opening more group homes, that would be good thing. Uh, sort of that, I know a lot of families are very, very, very desperate and not knowing—if there's going to be a place for their child. . . . I would tell other parents that they should definitely look at the agency and begin planning and learning about opportunities early on.*

Within the context of the need for external support, the recognition that PARENTS CANNOT BE CAREGIVERS FOREVER also occurred. A pervasive sense of the need for support dominated all the interviews with parent caregivers until they were ready to see that PARENTS CANNOT BE CAREGIVERS FOREVER and make residential group home placement decisions for their adult child with ID/DD.

Emilia and her husband worked with a service coordinator for many years who assisted them with the application process for their son Carmine. She and her husband felt they needed to learn about the residential group home system. By doing so, it is her opinion that this enables parents to move forward recognizing that PARENTS CANNOT BE CAREGIVERS FOREVER and ready for placement decision. They tried attending family support groups; however, the experience was not appropriate for them.

*We always worked with a, um, service coordinator from \_\_\_\_\_. Our service coordinator still is through \_\_\_\_\_. And, um, probably which fill out the, the application, the universal one, and submitted it and then we just kind of hung out and waited and, and figured, uh, something will come eventually. . . . You have to learn about it and if you don't, if you have the materials to understand it a little bit, I think you can both cope and, and move forward. . . . You know and we did, um, go to \_\_\_\_\_ had a, like, a parents group and we decided we would go to that but we abandoned it because it seemed to be a pity party. You know it wasn't—it didn't suit our needs at all, um, it was good to hear what other children were doing at different ages, that was informational, but it mostly was people who were sad and couldn't cope. So we moved out of that. . . . But, um, in the decision-making process sometimes people need to sit down and just talk on a, on a one-to-one. More comfortable than in a group.*

The support Emilia and her husband received prior to the residential group home placement of their son guided them to the point of readiness. They had already fully realized that PARENTS CANNOT BE CAREGIVERS FOREVER. Emilia explained the individual support she had received from a social worker the Life's WORC organization really made a difference for both her and her husband before and during the transition process.

\_\_\_\_\_, I had never even heard of the organization, out of the blue sent us a letter or called us—we had been away and we came home and then we got this, uh, phone call saying that they were interested in doing a meet and greet. So we looked at each other and said, “Oh. He needs to be going there.” Because it was one of those things that you’re waiting for, hoping for, and dreading all at the same time. So we did go to the meet and greet and, uh, they interviewed him and interviewed us and it was a, it was a good process and a real, uh, lengthy enough that you, you know, you felt as if they knew you and I felt as if we knew them and, uh, it worked out. . . . Yeah, and, and explained to her this is a little bit more difficult than we thought it was going to be both for us and, and for him. So we went in to her office maybe once a week for I guess maybe about a month and just sat and talked about it. And I thought it was, it was so nice of her to give up the time to do that and, and, you know, it really kind of made a difference, I guess, to us anyway. . . . But if someone who was faced with a decision and, and got the invitation for their child to be in a group home if they had somebody to talk to. Yeah, it probably would be a good thing. Because, uh, there really was nobody to talk to about it. Um, that’s why we reached out to her. So when it came, you know, time for Carmine to go the day that he went, um, it was, it was finally like it’s finally here. You know. It’s like something you’re dreading and then finally came.

Betty and Raphael had the good fortune to work with the same social worker for many years. The person who supported them was realistic and assisted and guided them through the placement journey. She encouraged the parents in earlier years to get their daughter Laura’s name on a placement waiting list. The social worker advised them of the reality of waiting too long, possibly resulting in their daughter needing emergency placement when the parents are no longer able to care for her. Betty and Raphael accepted that PARENTS CANNOT BE CAREGIVERS FOREVER and were ready to explore residential group home placement.

*Conventional wisdom 30 years ago was that there were no group home beds available, that you put yourself on the list and you only got to the top of the list when you were 80 and had one or both feet in the grave and you couldn’t care for your kid and now you’re 60-year-old child is gonna get admitted to the few—to one of the few beds that is available on an emergency basis. So she encouraged us, “Put your name on the list,” and she said to me, “What do you think?” and I said, “Well, I don’t see any harm. There’s no downside because we may never get to the top of this list and if we do and if it turns out that it’s not right they’re not gonna call her a prisoner; we take her back.” And it was to our great surprise that Laura still—was only 20, she still had a year to go in school, and we got a call from the same social worker who said, “You know, one of my jobs is to post—you know, after aging out is placement in residential and day programs and I’m in touch with all of the organizations and when they’re gonna put a new house together they try to group people of similar ability or disability,” and she was*

*approached by \_\_\_\_\_ with plans to put up a new house and she said, “Laura would be a perfect fit. What do you think?” and we said, “Wow, we didn’t expect this but” . . . we had a long talk.*

Betty and Raphael were concerned as to how they would know this was the right decision. They questioned how they would know if their child has made the adjustment. They attended a couple of meetings for families of the adult children with ID/DD that were scheduled to move into the residential group home.

*There were one or two meetings where we had met each other, I think it was more for the parents to support each other you know and for this transition. . . . And one thing that stuck with me is we were told, “How will you know that your child has made the adjustment?” He says, “You’ll bring her home and she’ll ask, ‘When are you taking me home?’” and that happened pretty rapidly. You know we brought her—we picked her up for a weekend and you know, “All right, this has been great. When are you taking me home?” Wow.*

Theodore was an adopted child whose development seemed normal early on until he was diagnosed with Asperger’s syndrome. It was then his mom Jennifer was told by a neurologist that Theodore will need a supportive living environment, that he would never be independent. Jennifer was ready and began preparing her son for this future placement. Jennifer knew that PARENTS CANNOT BE CAREGIVERS FOREVER. In order to plan for the future transition, she sought out the support of res-hab workers, respite workers, and respite weekends. Respite can provide a family temporary relief from caregiving demands. Respite services and supports can be provided in the home or out of the home any time day or night. A respite worker can come to the family home to provide relief, or the family member with ID/DD can participate in a short stay residing in a respite home (OPWDD, 2015).

*Theodore has, you know, multiple issues—um, my neurologist told me a long time ago that Theodore will need some kind of supportive environment. He will never be an independent adult, even though he is very bright. He just has too many organic psychological and neurological issues, so I knew that my goal would be residential eventually. So I didn’t feel it would be good to go from nothing to residential. So I did it over the period of ten years where he had a respite worker, a res-hab worker, and respite*

*weekends. . . . The respite houses, because they're run like group homes, really, um, he was involved with so many of those that I think that that was part of the, um, um, transition made it easier for him because of that. And he knew what it was going to be like for other people to take care of him. So the transition into residential was going to be much smoother. So I planned this for a very, very long time.*

Jennifer began planning early for other reasons as well. She wanted to be able to help negotiate the system with her son Theodore. She does not believe that planning when an adult child is 40 or 50 years old will be successful, and planning must begin much earlier in the life of the adult child with ID/DD.

*"This is not because mom and dad don't want you to live with you anymore. It is really for future." And I also strongly believe that you don't take a disabled individual at the age of 40 or 50 and think that that's gonna work. You need to start at an age where I'm around to help him negotiate the system and get him to understand how it's gonna work so that by the time he's 50 or 40, hopefully, every issue has been resolved. . . . I needed to get him through high school, graduated, into his day-hab, which was another lot of work to make sure I found the right day-hab. Get him transitioned into that situation, and then the next transition was gonna be into the group home, and that's exactly how it worked.*

Jennifer was pleased with the support the agency provided during the transition process of moving her son into the residential group home. They organized meetings so that families could meet one another and the other housemates.

*Yes, \_\_\_\_\_, um, had like breakfast meetings once in a while to meet the other families and to meet the other housemates, so they did a great job in transitioning Theodore. It wasn't like one day he was home and the next day he moved in. They had, you know, a few meetings before. Um, the day, of, um, move-in. They made it like a college move-in where everybody got a different hour. Um, everybody moved in on the same day. Um, they, they really worked very hard to make the transition as easy as possible.*

Like many of the parents, Jennifer is a proponent of support groups for the families. She has developed some, participated in others, and continues to advocate for the development of different support programs. The adjustment after the decision for placement and the transition of adult child into a residential group home is an ongoing lifelong process for the parents.

She attributed the success in the group home to a team approach.

*I've been in many, many, many support groups through the years. I mean, starting at \_\_\_\_\_, um, I did that support group. I did, did the \_\_\_\_\_ which is no longer available. I did that support group. I have a support group at my church. So I've been in support groups through this entire process. And that does help to be involved with a, with a support group. And to this day, I, um, my friends that I see most and I communicate most with are the families that I started out at \_\_\_\_\_, so we, we have our own little support group, whether it be by phone or socially with the husbands. Um, we, we're talking all the times because our kids started at \_\_\_\_\_ and at 2, and now they're all turning 25. So 23 years we're supporting each other because they all have different issues. . . . And the more support they can get, the better off they are and if you use the team approach is what I firmly believe in, um, I can't imagine that with a nurse, a house manager, a behaviorist, a mom, a dad, a sister, that that's not gonna work. . . . It's also very hard to give up control. Um, especially when you're a very, very involved pa—parent, um, it, it's very different to hand your child over to an agency and now they're in control, but it doesn't really have to be that way if you work as a team. So I think if you put your, your effort in to make it work together, the transition is much easier. Now some parents might not want to be involved. They, they feel, you know, "Enough already. I've had it. Now let them do it." That's a different situation. I never felt like, like that way, and I never will. I want to be involved. I want to know what's going on. Um, I wanna know what is in Theodore's best interest.*

Jennifer explained how the parents' readiness and their positive perception of their decision affect the transition process for the adult child with ID/DD. The adult child needs to understand that the residential group home is his or her new "home."

*I think that the first thing is the parents have to be ready. If you hear this and you're not ready, it's not gonna work because you're gonna go in there and you're gonna find a million things to complain about, and then you're gonna make the, the adult or child anxious about the decision. You have to be positive about it. That's the first thing, so that the child will be positive about it. You have to believe in your heart that this is the right thing to do. You also have to be realistic that it's not home. You're not the mother anymore. I, I've told Theodore that they're number one now and I'm number two, and he goes, "Really?" I said, "Yes, Theodore. This is your home. They're in charge. I'm number two. You have to understand that." That's hard for me today, but that's what he has to believe. Um, I think that you have to think about the future. Parents that don't are making a very, very big mistake. I think the longer you wait, the harder it is. . . . And I'm not gonna say that it was an even division because sure, I would love to be in control and be his mom and his caretaker for the rest of our—his, his life, but I know that that's not realistic.*

Rita looked for support on Long Island among families with a child with ID/DD. So many of the adult children know each other, but they have to be "out there" involved in things.

She described the collective population as a family. She believed there was a need for support groups and for parents to seek out friends that have children with special needs.

*But you do, you have like—you feel like a family, you know, you all know—especially now that the kids are older, everybody knows everybody. Every child knows, you know, in their 20s, on Long Island, with special needs knows the other—if you're out there, anyway, I should say. There's a lot of kids that are just staying at home and not doing anything. But like Racquel goes to the \_\_\_ in, um—on Thursday night they have a young adult program. Every single kid there knows everybody, and heard you got a new roommate, she knew all those people—her bowling team there . . . you know, you need the support, especially when they're younger. We had a support group. I mean that's a big part of what you need, so—and then you kind of find your friends that you have things in common with. . . . You know, it's the same thing, I would talk to my friends about, you know, and Racquel wasn't too thrilled about going there, so I guess I really looked to my friends, you know, some of them that have—a lot of them have special needs kids.*

Prior to Rita making her placement decision for her daughter Racquel, the organization providing the residential group home placement had a couple of meetings. Once she was ready to make the decision for placement, the events that followed happened very quickly. The meetings were not extremely beneficial to Rita because “she didn't know what to ask.” Rita did not feel the meetings alone were enough support, and would have liked to have had someone sit down with her and explain the process.

*Like everything just happened so fast, in like three weeks she was in the place. So it's not even like I had time to think, all I kept thinking was, well, this is it. . . . I guess I didn't know really what to ask. I just—and like I said, we had a couple of meetings with the people from \_\_\_ but everybody was like kind of—the questions that I had they were very lackadaisical and kinda like, oh yeah, that's not gonna be a problem. So I don't know, I just kinda jumped in and then kind of—still trying to figure things out. . . . But it would have been nice to have had somebody really explain things. . . . But I'm just saying, it would have been nice if there was a place to—that I could have gone to and a woman would have said, well, this is what I do with my child and this would be good for you, you know, to have these things in place before she goes. So yeah, it would have been a lot better.*

MaryAnn spoke about the support she had from her children. Her six other children were caring, kind, and supportive when she and her husband were ready to make the placement

decision for her daughter Marissa. The other children realized that their PARENTS CANNOT BE CAREGIVERS FOREVER and were in favor of and fully supported the placement decision.

*So I—when we told the boys, I started to cry telling them that we were looking for a place and I think we found one in Yonkers, and I started crying, and they said, “Mom, we think you’re doing the right thing.” . . . And they said to me, “How long did you think she was gonna live here?” And I said, “Well, I kinda hoped until she was at least 21 or 25. I don’t—” They said, “Are you crazy?” . . . And they were so young, that really—was balm to my soul, because I was a wreck.*

MaryAnn vividly remembered the day she dropped Marissa off at the residential group home. She recalled how she wished someone had given her “permission to leave,” that it was okay to go. She felt so torn leaving and just wanted someone to say, “It was all right, we will care for her now.”

*Then we followed the van over and it was time to eat, I think when we got there, and they just started feeding her, and I hung around. But you just sort of feel like you wish someone would say, well, now it’s time for you to go. And you can come any time you want. You know, the release, I call it. I felt like that’s what I could have used, “You can go now, we’re gonna take care of everything, she’s safe. Marissa, say goodbye to your mom and dad.” You know, give us that cue.*

MaryAnn and her husband were getting older and realized PARENTS CANNOT BE CAREGIVERS FOREVER. They were ready to make the decision; however, at the time of the interview, she admitted that she still feels a state of sadness.

*You’re always grieving, it’s a permanent state of affairs. I’ve really come to realize that, that it never leaves you, you always feel slightly sad. Just slightly sad of the loss, that you couldn’t be the one to make her life nice. All the others, I could make nice. I could soothe them. With Marissa, she needed something out of my, uh, expertise. And my husband too. You know, you could put kids in college, you could do this, you could do that, you could talk to them about their jobs, you can encourage them and you can give them faith that everything’s gonna be okay and yada, yada, yada. But with Marissa you just took one step in front of the other. And it’s—maybe that isn’t really right to say that because it sounds too sad, but I’m not sad, but I know how I feel, it is a certain like a loss, yeah, a loss in your life, a big—a big area that you could never really—yeah, I fed her, yeah, I helped her, I fed her, but you want to do more, and you want more for your child, but she couldn’t even have it. So that’s a little loss.*



Karen cared for her daughter Kristen with Prader-Willi syndrome into her teenage years and thought she would always be able to care for her. It was when Kristen entered her teenage years that she began to realize that PARENTS CANOT BE CAREGIVERS FOREVER. The idea of placement was always a thought in Karen's mind, and at that point she was ready. Her other children were supportive of the decision.

*Um, I had to say it was always in the back of my mind but never—I never entertained it until I have to say probably her teenage years because I just thought that I would always take care of her. Um, but as time went on and she needed more, you know, really more assistance as far as the eating and, um, her temper tantrums, I knew that eventually, you know, she was probably gonna have to live, you know, in assisted situation. She couldn't stay at home anymore. . . . Um, my children were because at that point they were older so they, they knew that it was the right thing to do because they lived with her. They saw what, you know, what was going on at home. It was actually harder to take care of her when she was an adult than when she was a child.*

Karen expressed how the placement decision has changed her and her other children's lives. Once her daughter was moved out of the family home, she realized the amount of stress she and the rest of the family were under while caring for her.

*Uh, quiet in the home, very quiet, uh, less stress as far as, you know, worrying about her and her health, of course, you know. A lot less broken things. [Laughs] Uh, my other two children also. It's a lot easier on them because they would witness all the outbursts so it's quieter at home. That's for sure, you know. It's, um, they're older now also so they understand a little bit more with her hardship, too, and they see what it was doing to me, so I think every, you know, everybody just is kind of calm, very calm.*

The support of Karen's family, and the way the organization handled the transition into the residential group home assisted her with the difficult decision and the transition process to follow. Although personally she was not involved in a support group, she thought it could be beneficial for parents who may be interested in participating, or for those who may not have the support of friends and family.

*And I have such a big supportive family and friends so that helped me through, so maybe I felt I didn't need that. Um, but I do think it's helpful. I do think if they do have, you know, a support group for the parents to make them realize that they're not doing*

*anything wrong, you know, that might be a little bit helpful, you know, just for the parents' sake. Did we see—I didn't see the house before she went in it. Trying to remember. It was more like a "Yeah, she's going here, blah, blah, blah." Going into \_\_\_\_\_ I didn't see but going into \_\_\_\_\_ I did and I liked that. I liked that they didn't just send her there, that they, you know, invited us over to look at it and see what it was about. I liked that part of it, so I would recommend that, you know, make the whole family do it, go into it, you know?*

Eddie was fortunate to have a great deal of family involvement. Her family supported her and her husband throughout the years with both physical and emotional assistance with their son Robert. Robert was diagnosed with agenesis of the corpus callosum and autism. Eddie watched her parents assist them with Robert until they began aging and were physically unable to do so. She began to see this happening to herself and her husband. Her need for readiness to consider residential placement became apparent to her that PARENTS CANNOT BE CAREGIVERS FOREVER. Robert was becoming more physically aggressive and a behavioral problem. His behaviors and unpredictable nature of them were becoming too much for his parents to manage. The decision was made for group home placement. The family had the assistance of a service coordinator that guided them through the application process.

*What I did was I worked with my service coordinator, and I had her fill—she filled out a lot of applications for me for every agency. At that time, you, you submitted them to the different agencies.*

The parents received a call rather quickly about possible placement. They were not expecting to be contacted about an opening for their son as soon as they were. It was a house that was already established with six men. One individual had dropped out of accepting the placement opportunity, leaving a place for Robert. The family went to a meeting where the individuals and the parents could meet each other. Eddie and her husband used their faith to guide them about the appropriateness of their placement decision.

*At the time and everything, this was a house that was already establish—ah, was they had their six guys, but one of them dropped out, and they called me and said, "We're gonna*

*have a meeting. The guys are gonna meet each other. The parents are gonna meet each other. It's a new home. Would you like Robert to come and meet the guys? You wanna consider it?" So we're like, "Oh, geez." Now what? But we just said, "All right." We prayed about it. We said, "You know what, Lord? If this is the right placement, you know, just help us to step—move forward—and open the doors." And that's what happened. We went and it just looked right, you know? The guys looked right. The—it, it just seemed right. But it wasn't all that it seemed. But at the time, it seemed really good, and so we said, "All right. We're gonna step out in faith and do it."*

One of the particulars Edie likes about her son being in a group home is the team approach of coming together when Robert has a crisis. She feels confident in the abilities of the healthcare team in the residential house to handle a crisis situation.

*For the main things, as far as Robert's support and the team approach, it's very good. That's the thing I really do like about him being in a group home as opposed to being, being home. When he has a crisis, we come together and we work as team, and we brainstorm and we get him through it. When he was home, it's like who do you call first, 'cause it's so disjointed? You don't have team approach. So that is something I really, really think is a big benefit. . . . And for us as parents because at least he could be in a tough crisis, but at least you walk out saying, "Okay, there's hope." You know, we—you don't, you don't go crazy. You know, you just get together and say, "All right—they're very good at that." I'll say, "Well, we need to meet." We meet, and we do resolve for, for a time and see what happens. . . . I mean I'm very, very, very fortunate that I have good support. We do have good support, we do. Can't—you really can't complain 'cause I look at parents who are waiting for placement, it's hard. They have kids who hit, beating them up, and, you know, all this stuff.*

Like many of the parents who have made the decision for residential placement, Edie reinforces the importance of staying involved in one's adult child's life after placement. She has developed relationships with other parents. She is willing to talk to others about her decision. Her faith has guided her and helps her feel confident with her decision. She has accepted that it "is okay" that she could not be the caretaker of her child forever.

*You know, you have to stay very involved. Don't go into it thinking that, you know, everything's gonna be wonderful, 'cause it's not. You have to be involved and you have to, um, you know, keep trying to strive to make it better for them. Your job's not over once they're placed. . . . I have relationships with some of the parents. There's one in particular I care not to have any relationship with. Um, but for certain reasons. But, yes, I have a relationship with Danny's parents and, um, David's sister. And, um, James' father's not around much. Yeah, that's it. The three—us three, we—mostly Danny's*

*mom. We've become very friendly. Yeah. Very friendly, you know, we, we go out and stuff, so it's—yeah, she's a very good support for me, and I think hopefully, I am for her, too. . . . Maybe talking to other parents. Um, what helps me is I—my faith. I mean I—so I can't tell other people what to do in that area, but I know that, you know, it's—I know that, ah, you know, I, I did pray for—pray about it and we did put it in God's hands and he did open the doors. So I felt comfortable—that that was it. But I still say, "Did I do the right thing?" I'm asking, "Did I do the right thing? Maybe he'd be better off at home." You know? But don't beat yourself up and don't feel guilty that you can't take care of your child. That's the main thing, 'cause that's the biggest thing for parents.*

Debra remains a strong advocate for people with autism. She had multiple relationships with people in the OPWDD system and was encouraged early on to put Stanley on a list for residential placement. She explained that when she put him on the list for future residential placement, she was not ready at that time to make the decision. However, she knew the process would take several years. When the opportunity came for placement, she was ready to make the placement decision. Debra and her husband could no longer care for her over 6-foot-tall son who was increasingly aggressive and difficult to manage in the family home. She was accepting that PARENTS CANNOT BE CAREGIVERS FOREVER.

*"Get him on the New York Cares list. Get him on it at 15. You won't have a group home for seven years." I think he was—almost hit it to the nose. He said, "If he, if you cure him, you get him off the list." He said, "But, but—and it was also, um, oh, she died. And she was \_\_\_\_\_ woman. And she said, "Yes, get him on the list." She said, "It's gonna take years." And I never—I was not ready at—now this gets to the heart of your thing. I was not ready at 15 to put him in a group home. I was far from ready. And, um, I now advise parents if there's a place at 15, 14, 13, think of it as boarding school, and put 'em in because it's not gonna be anyplace. Take it now. But we didn't have that. I mean it wasn't—we, it wasn't, it wasn't so many. It wasn't the situation. But, um, everybody was exhausted.*

After Stanley was placed, Debra turned to her friends who also were parents of children with autism. They were her support following her decision. She also has suggestions on what organizations need to do. Like other parent caregivers, she recognized the need for the organizations to better assist the families with the decision process, to "hold their hands and support them all the way through."

*And, and, um, just girlfriends of mine, women friends, you know, people who, other autism mothers who were my really best support. They were saying, "Well, what'd you think? You've been a caretaker. You've been organizing his life from home since—you know, for a really 22 years, but for, you know, minus 19 of them with autism. All of a sudden, it all leaves. You think you're gonna feel great right away? No, you're gonna feel awful." So, um, he, um, the—my friends, women, they said to me, "What—you know, what'd you think? You thought it would just be smooth sailing?" I mean I was—"Of course, you're depressed. You know, of course. Of course." I felt awful, awful, awful, awful for a few years. And then, you know, I was starting to feel better. . . . What I felt—and I've said this to the \_\_\_\_—I said, "What you need to do is you need to hold the hands of parents before, during, and after, and you're not doing that." . . . What I felt is that I wanted somebody to alert me to have—I wanted the \_\_\_\_ to have a group. I wanted the \_\_\_\_\_ to really assign me a social worker or somebody who knew this before he went into the group home, when he when, and after, and follow me through the process. Tell me what to expect. Talk to me when it was happening. Talk to me when I thought it should have been over. That's—I, I know I said that, but I want to make that really, really clear.*

Talia had been coordinating with her social worker and filling out the necessary applications. She had been told that placement could sometimes take many years. Several years ago she received a call shortly after the application process. At that time she was not ready to make the decision, and she took too long to even consider the decision. She and her daughter missed out on that particular placement opportunity, as it was provided to someone else.

*I'm not ready for this so, uh, anyway I hemmed and hawed for I would say a good week and a half to two and then somebody who needed it more than her needed it and they got it. I think [crosstalk] if I would have said yes, I'm thinking if I would have said yes and got her right in there I would have secured that placement. . . . Yeah, I really wasn't ready, I really wasn't.*

Several months ago Talia and her family received a call regarding the residential placement opportunity in several homes with various organizations. It is quite unusual to have a selection of possible residential placements. Due to her daughter Angela's symptoms associated with Prader-Willi syndrome, Talia and her family selected a home that best matched her daughter's needs physically and psychologically.

Talia and her family knew that the time would come when she would need to find a group home placement for Angela. She and her husband's readiness came over time. Talia explained that in retrospect knowing that this will ultimately be the decision made that she "would have not spent so much time worrying about the inevitable."

*I don't think I would have put my—I don't think I would have tortured myself all my life worrying about that—that day that came. I—I mean the hours that I spent worrying and wondering, well, if I do put her in a home, well, it's gonna be terrible. She's gonna think I bet—you know, and maybe, maybe to some degree that's happening but it's working. I wish I didn't put myself through all that for all those years. . . . I think it might help them maybe like my friends and whatever helped me. If I could say to a parent who has a child like mine that's five years old and say, "Listen, don't spend the next 20 years worrying about it—because it's—you're probably gonna come to this decision, it's going to work out great, don't spend 20 years of worry. You know, nothing's all-consuming but don't do it."*

Talia described the decision as a type of "mourning" and specifically that there is a process to it. She thinks each family is individual in going through this "process" until the point of readiness.

*And I think like I said, I think it's like mourning and I think there is a process to it. You know, when you make—when you really come to this decision you are whatever it is, guilt, all—all those—you've kinda have to do it. . . . So, uh, I don't know. But I wish I could tell parents. It's going to be fine and work out. I'm only two months into it and I'm thinking, you know, again I miss her. I'm gonna have days where I'm—right now I'm just—it's good, it's good—we're gonna make it work and there's gonna be days when I'm just gonna cry 'cause she's not here.*

Talia was so pleased the phenomenon of how parents make the decision about residential group home placement for their adult child with ID/DD was the focus of this research study. As a parent she was aware that this is an area that represents a gap in the research literature. It is her belief that if other parents are aware of how people made the decision, it could help them in the future with their own decision-making process.

*Maybe if you, you know, maybe be enough of these interviews, if enough people that have done it say—I mean I don't know what other people are saying, but if enough people say it's been a process and it's been a right decision maybe that would help a parent in the*

*future. . . . Exactly. So maybe if it's really in writing, well, your paper—maybe your paper will. I mean you know your paper will. Nobody does research on this stuff or these kids. Right.*

**Contrary case: Support system.** Valerie lost her husband over 30 years ago in a motor vehicle accident when Joey was just a teenager. Throughout the interview, she continuously reiterated that one of the greatest challenges was not having a companion to talk things over with. She has limited family, having only one sister who lives out of state. However, her late husband's family has embraced her and continued to be a support to her. In addition, Valerie has her other children who assist her, some of whom still live at home and help with Joey's daily care.

Although over the years Valerie has reached out for services for Joey, she seemed to be lacking the knowledge of benefits to which her son was entitled. Being a single parent raising five children alone, she expressed that her time was limited. “She just needed to do what she had to get by day to day.”

*For the most part I had to do it alone, I raised five kids that I am proud of how they have all turned out. No one is involved, or was ever involved in drugs or crime. That's because I made sure I was there, trying to avert trouble. I made many sacrifices, but it was just the way it was and I would do it all again in a minute. I tried to do the best I could. I took jobs that allowed me to get my children to school in the morning and be home for them when they go after school. I ran them around to all their afterschool activities. Joey was always along for the ride. My husband's family was a support to me when he was alive and embraced me after he died, to this day are still a support. You know, I don't have any family, other than one sister who lives out of state. She was my rock when my husband died; she comforted me and go me through some very difficult emotional times. Maybe I didn't pay enough attention to Joey as he was growing up? He was one of five, and I am only one person. I had to try and divide myself fairly to each of them. Maybe if I devoted more attention to Joey he would have been able to do more? Maybe if I had looked for every possible service maybe he would be different? That is something I'll never know, and something I cannot change. Part of it was me, part of it was the system. I know that, I changed service coordinators when I realized that the person was not as competent as they could be. I did what I could, I did the best I could. But once he aged out of the system at 21 years of age things are not available for him, the school is no longer responsible, and there are not a lot of options out there of things he can do, or participate in. That's when I obtained a res-hab worker, but that has not been*

*consistent. My kids used to be more involved with Joey, they are just not able anymore. As I mentioned earlier I have recently accepted that I cannot do this care taking forever, and that I won't be here forever. I need to learn what is available, I suppose it's better late than never. [Laughter]. I know I do.*

Valerie's responses during the interview indicated that she has appeared to struggle over the years about not knowing her available resources and would benefit from support to become more knowledgeable regarding the OPWDD system. Perhaps with proper support from the service system she could have received the guidance and support within the system she seemed to lack. When her son aged out of the school system, she was not prepared with the necessary knowledge for the transition out of the educational services. However, at this point in time she recognized that PARENTS CANNOT BE CAREGIVERS FOREVER and expressed that she was ready to begin conversations with her own children as well as the appropriate resources.

### **Summary of Findings**

In this chapter, a substantive theory has been presented that identifies, describes, and helps to explain how parent caregivers manage readiness to make a residential group home placement decision for their adult child with ID/DD (see Figure 1). Parent caregiver readiness is the basic social problem experienced by parent caregivers as they care for their adult child with ID/DD and make residential group home placement decisions. The core concept and the process by which they resolve this problem has been identified as the recognition that PARENTS CANNOT BE CARGIVERS FOREVER.

Making a residential group home placement decision for an adult child with ID/DD is a process that occurs and changes over a period of time. Based on the data from these interviews, it appears that the core concept PARENTS CANNOT BE CAREGIVERS FOREVER explained the residential group home placement decision-making management as a process of perceived readiness for parent caregivers of those with ID/DD. During data analysis and the insights



achieved from constant comparative analysis, the core concept occurred frequently in the data with other categories and theoretical constructs related and attached to the main core. The core concept of PARENTS CANNOT BE CAREGIVERS FOREVER is the central idea that emerged from the data and is able to explain variation in the information. This core concept informed a substantive theory that describes and helps to explain the phenomenon of parent caregivers' decision-making process, and was derived from theoretical constructs that were grounded in the data. Four theoretical constructs are associated with the recognition of PARENTS CANNOT BE CAREGIVERS FOREVER: normalcy, burden, mortality, and support system. The major theoretical and subcategories are outlined in Figures 2, 3, 4, and 5.

Parents want their adult child with ID/DD to experience normalcy including the natural progression of moving out of the family home into a more independent setting with support apart from the parent caregiver. They want them to have recreational, social, and leisure activities; to have a functional role in society; to experience relationships with peers; to develop skills for successful daily living and good physical health; to be safe from danger or harm and have psychological well-being.

Parent caregivers were also concerned of the possibility of the adult child with ID/DD one day becoming a "burden" to siblings or family members when the parents were gone or no longer able to care for the person. This concern helped to propel them to be ready to explore the decision-making process as well as the recognition PARENTS CANNOT BE CAREGIVERS FOREVER.

Parents recognized and came to the acceptance of their own mortality. They accepted that they would not be here to care for their child forever. As they aged, caregivers began to

recognize their own physical limitations. That realization prompted them to be ready to plan for the future of their child with ID/DD.

In addition, the need for a support system to assist with proper planning, available options, and the optimal transition to a residential group home for their adult child with ID/DD was a common thread throughout the participants' interviews. This support system included friends, family, members of the interdisciplinary healthcare team, and particularly nurses.

A substantive theory was developed focusing on the essence of numerous case instances represented in the data in a parsimonious relational structure. The constructs' similarities of normalcy, burden, mortality, and support system were a common thread in all participants' interviews. These constructs were used to assist the parent caregiver with the recognition that **PARENTS CANNOT BE CAREGIVERS FOREVER**. The constructs and associated strategies were utilized until the parent was *ready* to make the residential group home placement decision. Parent caregiver readiness was identified as the basic social psychological problem.

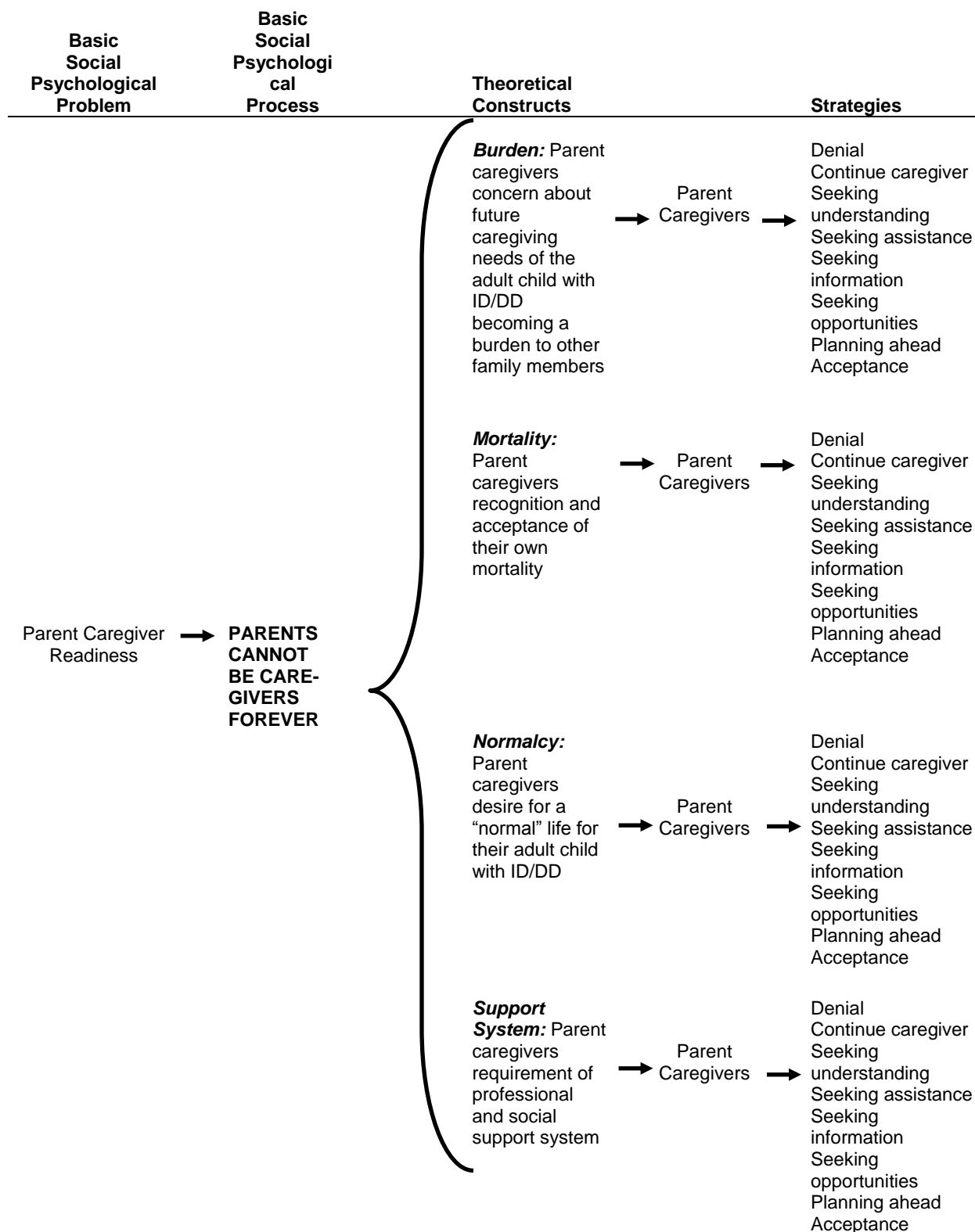


Figure 1. The substantive theory: Major theoretical constructs

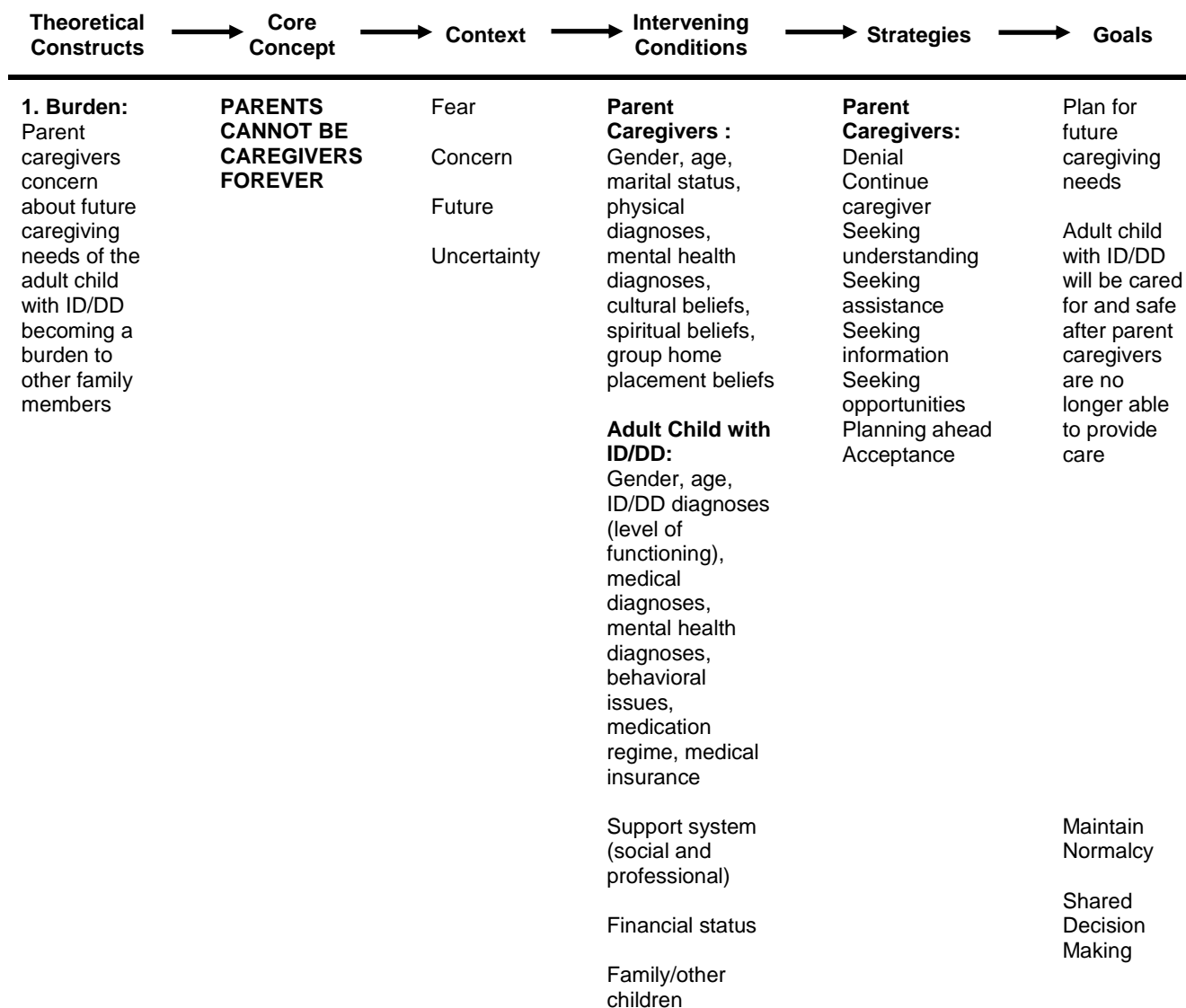


Figure 2. Diagram of PARENTS CANNOT BE CAREGIVERS FOREVER: Burden

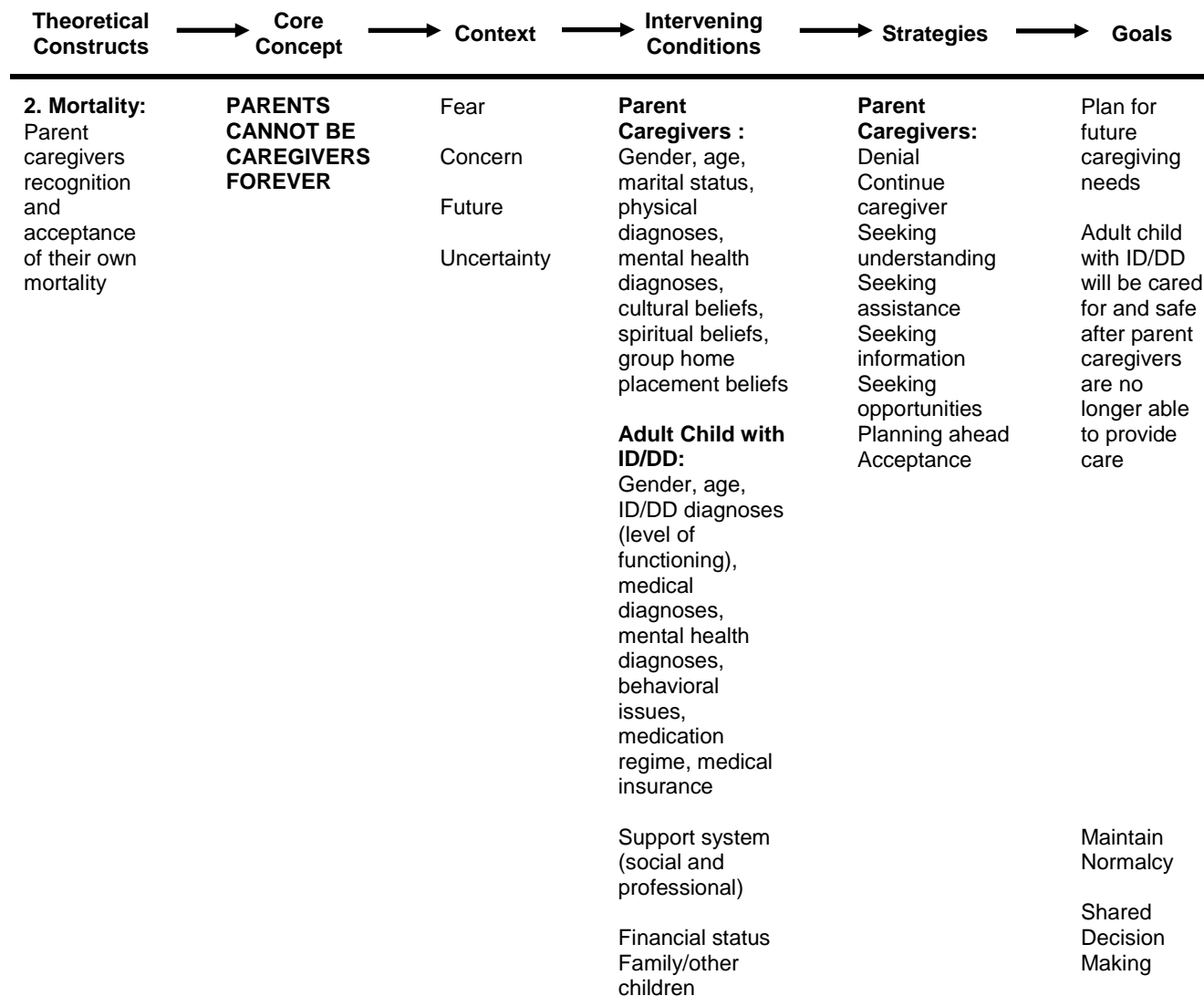


Figure 3. Diagram of PARENTS CANNOT BE CAREGIVERS FOREVER: Mortality

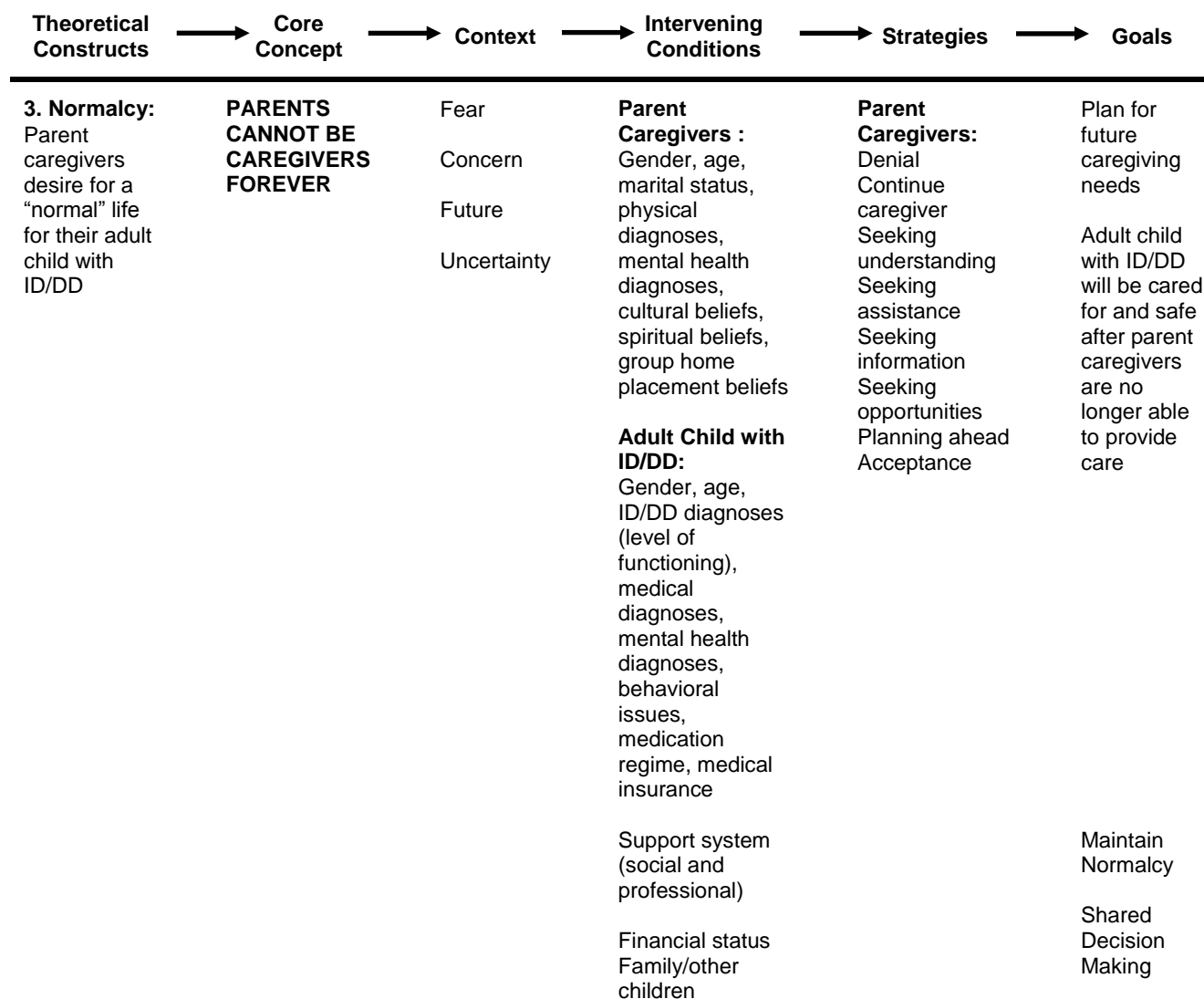


Figure 4. Diagram of PARENTS CANNOT BE CAREGIVERS FOREVER: Normalcy

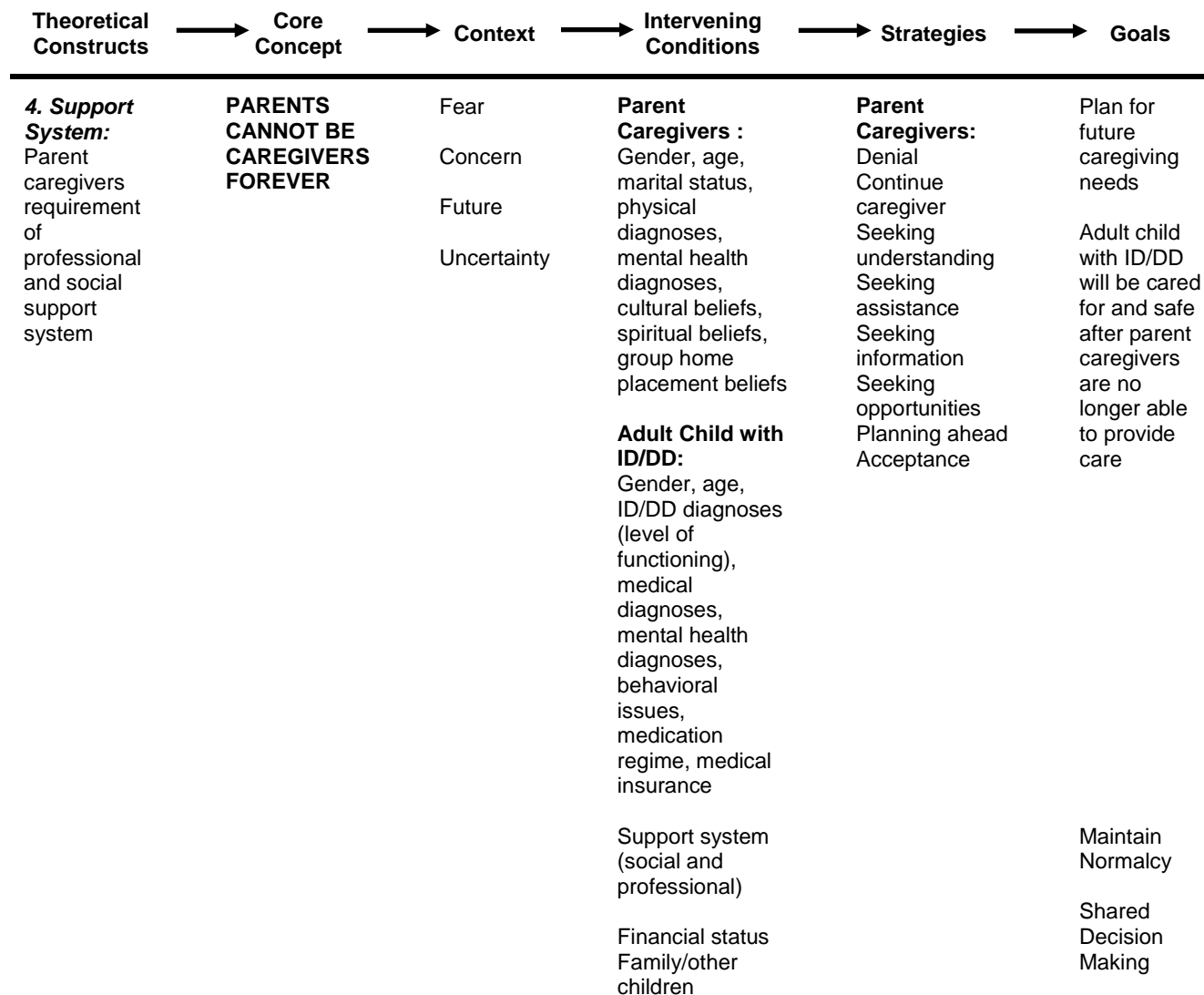


Figure 5. Diagram of PARENTS CANNOT BE CAREGIVERS FOREVER: Support System

## **Chapter 5: DISCUSSION**

### **Introduction**

The principles and underpinnings of Grounded Theory methodology and the core element of nursing practice fit together significantly (Gelling, 2011). The phenomenon being studied allowed for the inductive development of a Grounded Theory. The theory was generated through the systematic collection of data and subsequent analysis of the data pertaining to the phenomenon. With the Grounded Theory methodology, the researcher did not begin with a theory, but rather the theory emerged from the data (Strauss & Corbin, 1990). Grounded Theory both describes and explains the system or behavior under study and consequently is a methodology for developing theory that is grounded in the data, and then systematically gathered and analyzed through constant comparative analysis (Strauss & Corbin, 1994). Utilizing the Grounded Theory methodology, the researcher reviewed literature that pertained to the area in an attempt to provide an understanding and become familiar with the current state of the literature. This understanding of the current state of the literature assisted in determining where the study “fit” in the context of what is already known. Further review of the literature was conducted as a result of the data collection and analysis (Licqurish, 2011).

The purpose of this study was to develop a substantive theory that would describe and explain how parent caregivers make residential group home placement decisions for their adult children with intellectual disabilities/developmental disabilities (ID/DD). The researcher developed the research question after many years of experience working as a registered nurse caring for individuals in the specialized area of intellectual and developmental disabilities nursing. Over the years, the clinical-based practice experiences of the researcher included working with parents as they often struggled with the decision-making process for group home



placement, and the transition of care of their adult children with ID/DD into residential group home settings. A significant objective of this research was the contribution to the limited body of knowledge in the research literature regarding the decision-making process used by parents for how they make residential placement decisions for their adult child with ID/DD.

### **The Findings**

This chapter discusses the findings of this study. The findings presented are supported by the initial literature review after data collection and analysis, and by the rich, thick data obtained through study participants' interviews. Further exploration occurred with a secondary review of the literature that improved understanding of how these research findings advanced the science of the parent caregivers of adult children with ID/DD and the decision-making literature. Grounded Theory methodology was purposefully chosen after the research question was developed to seek a deeper understanding of how parents make the decision about residential group home placement for their adult children with ID/DD. Interviews were conducted in an effort to seek a symbolic, descriptive explanation of what is occurring from each parent's perspective. The researcher applied Watson's (1985) Theory of Human Caring to the interviews and theoretical constructs to more fully understand the parent caregivers' decision-making experience.

### **Major Findings**

1. Parent *caregiver readiness* was identified as the basic social psychological problem. Parents caring for adult children with ID/DD were unable to consider or make residential group home placement decisions until they had reached their own personal "*readiness*" to do so.

2. PARENTS CANNOT BE CAREGIVERS FOREVER was the core concept or basic psychological process used to resolve the basic social psychological problem. The core concept explains the residential group home placement decision making as a perceived readiness for the parent caregivers of those with ID/DD. Several theoretical constructs attached to the main core emerged from the data. The four main theoretical constructs to emerge from the data were the following:
- (2a) Normalcy: The parents had a desire for the natural progression in life for their child with ID/DD.
  - (2b) Burden: The parent caregivers were concerned that siblings or other family members not have the responsibility or “burden” of caring for the person with ID/DD when the parents are no longer able to.
  - (2c) Mortality: The parents reached a point in time where they were in acceptance of their own mortality. They recognized and accepted the need to plan for the future of their adult child with ID/DD.
  - (2d) Support system: The parents recognized that a support system can help provide membership into a community that can help parent caregivers in navigating and advocating for their adult child with ID/DD. Parents can receive information explaining the types of services and supports that are available. Parents go through many stages and adjustments throughout their life when caring for a child with ID/DD. It is imperative that information be presented to parents at a point in time when they are ready to accept the message. Through this research, it was also identified that it is important for parents to communicate with other families and have interaction with supports that offer a sense of what the future may look

like. By including the healthcare team and particularly nurses, parents will be able to adapt the information and participate in a shared decision-making process.

### **Discussion of the Findings**

#### **Parent Caregiver Readiness: Basic Social Psychological Problem**

The basic psychosocial problem in residential group home placement decision making that unfolded from the data was the parent caregivers' *readiness* to make a residential group home placement decision. Making the decision regarding residential group home placement can only occur once the parent caregivers have reached the point of "readiness." Through this research, it was identified that the parents reached the sense of perceived readiness when the theoretical constructs converged, leading to the core concept PARENTS CANNOT BE CAREGIVERS FOREVER. It was not until the parents reached this core concept that the basic social psychological problem of readiness can be addressed.

Caregiver decision making regarding long-term placement decisions was previously investigated. Using Grounded Theory methodology, Pastor (2008) investigated decision making by elderly community-dwelling spousal caregivers about long-term care placements for their partners with Alzheimer's disease. Thirty-three participants acting as spousal caregivers for their partners with Alzheimer's disease were part of the study to describe their long-term placement decision experiences. The interviews were designed to elicit decision-making patterns regarding decisions about caregiving. The research found that it was only when the spousal caregivers acknowledged the changing reality of the caretaking situation for both themselves and their affected partners that they were able to make caregiving decisions.

Identified in the data as the basic social problem in deciding about long-term placements was caregiver "readiness" to take on the caregiver role. "Seeing the changing reality" was

identified as the basic social process or core concept adopted by spousal caregivers in becoming ready to make decisions about long-term placement for their spouse with Alzheimer's disease.

### **Basic Psychosocial Process: PARENTS CANNOT BE CAREGIVERS FOREVER**

In this study, the discovery of the core concept informed a substantive theory that describes and explains how parent caregivers make residential group home placement decisions for their adult child with ID/DD.

It was discovered that when their child was diagnosed, parent caregivers initially believed they were going to be the child's caregiver forever. Parents had a strong desire to have their child live within the family and to be cared for by themselves for as long as possible. The parent caregivers who took part in this study were different in many ways. Their diversity was reflected in their differing views about their adult children with ID/DD, their plans for residential group home placement, their decision-making process, and their experience as the transition to the residential group home setting occurred. Although the parents were different in many ways, the commonalities of what they experienced led to the decision-making process regarding residential group home placement. During the interviews, the researcher was able to identify and interpret these shared experiences with four distinct theoretical constructs including normalcy, burden, mortality, and support system that led to the core concept PARENTS CANNOT BE CAREGIVERS FOREVER.

### **Symbolic Interactionism**

The core concept CAREGIVERS CANNOT BE CAREGIVERS FOREVER aligns with Blumer's (1969) theoretical perspective of symbolic interactionism. This is a sociological theory about human behavior and inquiry into human conduct. The meanings of things come from social interaction with others and the interpretation of the experiences.

1. Humans act toward things on the basis of the meanings that the things have for them.
2. The meanings of such things are derived from social interaction that one has with others.
3. These meanings are refined through an interpretive process used by the person dealing with the things they encounter. (Blumer, 1969)

Making residential group home placement decisions is a socially interactive process occurring between the parents and the adult child with ID/DD, and concurrently occurring with those surrounding them in their social circle. The parents make the placement decision based on the meaning the process holds for them. The meaning of the process and implications of the ID/DD diagnosis occurs over time as parent caregivers make meaning, sense, and define their caregiving experience of the child with ID/DD. The meaning of their caregiving experience occurs by examining their interaction with others, including the adult child with ID/DD and others related to the decision, and then interpreting the meaning of those interactions.

### **Theoretical Constructs**

Residential group home placement decisions by parent caregivers of the adult child with ID/DD is a process that occurs over time. The researcher discovered that when the parent participants recognized that PARENTS CANNOT BE CAREGIVERS FOREVER, they were then able to make placement decisions. The following four theoretical constructs that led to the core concept were the desire for normalcy in the life of their child; the parents' acceptance of their own mortality, the need for planning so that the child would not be a burden to other family members; and the recognition of the necessary support system to assist with a shared decision-making process with residential group home placement decisions.

**Normalcy: Parents' desire for normalcy in the life of their child with ID/DD.** The parent caregivers who were interviewed expressed many of the traditional attributes parents define as normalcy in adulthood and becoming an adult. They wanted the same for their children with ID/DD. Parents emphasized that, although the child was diagnosed with ID/DD, there were many things they wanted and expected to see their child achieve in life and for the child to be able to reach a level of independence and normalcy. Parents recognized that in order to achieve this level of normalcy, PARENTS CANNOT BE CAREGIVERS FOREVER. They wanted their child to have a sense of normalcy fitting the needs and level of abilities of the individual with ID/DD.

Over time as their child aged, parents saw how the child needed to have the opportunity to move out of the home apart from the parent caregiver; have relationships with nonrelated peers; be with people their own age; have an occupational or functional role in society; contribute to the community; apply for a job; have job skills training and supported employment; volunteer; join workshop environments; develop appropriate social communication, cooking skills, and community navigation; continue academic goals; be independent with the necessary level of support; participate in social, recreational, and leisure activities; and develop romantic or close relationships.

Although parents were able to define what they wanted for their child, over time as they themselves began to age, they realized they could not provide the level of opportunities they desired for their loved one. The parents realized that they could not provide care forever for their adult child with ID/DD and that PARENTS CANNOT BE CAREGIVERS FOREVER.

This finding that parents had a conventional view of normalcy in adulthood of the child with ID/DD has significant implication for future placement decision making. The parent

caregivers realized that the caring needs of their adult child with ID/DD were becoming more difficult to manage as both child and parent aged. Some participants expressed that the needs of the adult child were becoming too great and beyond their abilities to cope. Some of the adult children became physically difficult for the parents to care for due to the parents' own deteriorating physical conditions and the onset of illnesses that often coincided with similar issues occurring in the adult with ID/DD. Participants reported that many of the adult children with ID/DD had more frequent aggressive episodes, and were difficult for them to handle. Many of the participants reported "they just couldn't keep up" with the necessary responsibilities and normal daily requirements of the child with ID/DD and were feeling overwhelmed.

Parent caregivers used several strategies to adapt to the continuing increasing demands and the difficulty in maintaining and providing for "normalcy" for their adult child with ID/DD. Parents began to elicit the help of others, including family members and friends. They reached out for professional support through service coordination in an attempt for assistance and possible outside-of-the-home programming. In many cases, parents sought psychotherapy to help with coping with the emotional toll of the caregiving experience. Despite their efforts and the desire for a normal life for their children, they could not keep up with the demands of caregiving and recognized that PARENTS CANNOT BE CAREGIVERS FOREVER as they became completely overwhelmed with the intensity and duration of the caring efforts. The job of caring for a person with ID/DD at home is an extremely difficult one. The burden of caring for the adult child with ID/DD became extreme. With the desire to provide a normal life for their adult child with ID/DD, parent caregivers reached a point of readiness to consider residential group home placement decision.

A secondary analysis of the literature examined an integrative review completed by Boyles, Baily, and Mossey (2008) that explored the way in which disability has been perceived and considered in the interdisciplinary and nursing literature. Reported by the researchers was the lack of the identification of qualitative and quantitative research examining disability. The multidisciplinary literature on disabilities can be viewed in two ways: a traditional functional perspective and the more contemporary social perspective. The functional perspective focuses on the physical disability and can result in social stigmatization and normalcy. The social addresses functional limitations within the disability and the socially constructed barriers that actually disable the person with disabilities and prevent normalization.

Boyles et al. identified that a number of authors have concluded that society's view of people labeled disabled impacts the health and well-being of persons with disabilities. Nurses need to increase their understanding of disability and recognize their own beliefs, attitudes, values, and thoughts about disability. Nurses are in a position to advocate for people with disabilities and have the ability to transform people's experiences of living with disability.

Parent caregivers' desire for their adult children with ID/D to have a "normal" life can be impacted by many variables. The lives and the care of people living with disabilities can be positively influenced with nurses embracing a contemporary theoretical understanding of the language and the nature of disability (Boyles et al., 2008).

The findings from this research study are supported by the integrative review conducted by Boyles et al. (2008). Parents expressed the desire for their adult child with ID/DD to have the experience of "normalcy" in their lives. Nurses are in a unique role to promote normalcy in the lives of adult children with ID/DD. Once nurses have examined their own understanding of disability, they will be better able to engage people living with disabilities as active participants



in their care and decision making. This ability to understand and advocate for persons with ID/DD will enable the person with ID/DD to have a sense of normalcy in their lives which is free from stigmatization.

**Burden: Fear of the adult child with ID/DD becoming a future burden to others.**

Although the person with ID/DD is not “sick” in the context that we often define illness, they require lifelong care and support over their lifespan. This caregiving role differs from those in the general caregiving community. Caregivers for family members in the community who have developed short-term illnesses or injury resulting from an accident are of a limited duration. However, for parent caregivers caring for someone with ID/DD, caring is lifelong. The aging population of people with ID/DD continues to rise. The disparity between the life expectancy of persons with ID/DD and that of the general population will continue to decrease (Coppus, 2013).

Parent caregivers who participated in this study were very specific about not wanting to burden family members, especially siblings of the person with ID/DD, in the event they are no longer able to care for their adult child with ID/DD. They are faced with the question regarding the future needs of their adult child with ID/DD, who will care for them, and where they will live when the parents are no longer able to do so.

Parents described that caring for a person with ID/DD carries a significant burden and limits the ability for families to live normal lives. They did not want their other children or family members to assume the responsibility of caring for the adult child with ID/DD.

The parents’ realization that the adult child with ID/DD may eventually require care beyond what they can physically, financially, or emotionally provide brought them to the realization that PARENTS CANNOT BE CAREGIERS FOREVER. They explained how caring for the person with ID/DD impacted their lives and how they did not want their children or

family members to be burdened in their own lives later on. They also stated that it was not their other children's place to have to care for their sibling. Parents wanted the siblings to be there and advocate for the adult with ID/DD and do things with them, but not to be their full-time caretaker or have the person live in their house. Parent caregivers expressed how they wanted their other children to enjoy the company of the sibling with ID/DD and enjoy spending time with him/her "because it's not a front-line burden situation." One parent so poignantly said, "I don't want to burden my daughter, her husband, or her children with caring for a disabled adult. I want her to love her sister and not look at her as a burden."

A secondary review of the literature examined a study done by Ryan and Scullion (2000) exploring various factors that were the precipitants for families to make the decision to place their older adults family members in a nursing home. They found that family members expressed that, although after placement they experienced feelings of relief from the burden of the day-to-day care of their family member, they additionally had feelings of guilt that they could no longer provide the care.

The results from this research study were supported by Ryan and Scullion's (2000) findings. Several parent caregivers had reached the point where they could no longer provide care for their adult child with ID/DD. The parents experienced a sense of relief from the burden of care when they placed their adult child in the residential group home. However, many also had feelings of guilt and the desire to have been able to continue to care for their adult child at home.

**Mortality: Parents' recognition and acceptance of their own mortality.** One of the greatest concerns of parents caring for adults with ID/DD is the point in time they realize and accept that their children cannot care for themselves and wonder who is going to care for their

children when they are gone. With the ever-increasing life expectancy of persons with ID/DD, parent caregivers are caring for their adult child with ID/DD well into their own advanced age. With this extension of the caregiving period, parents begin to have their own health issues and conditions that often present with increased age. Due to advances in medicine, early diagnosis, treatment, and interventions, often children with ID/DD are currently outliving their parent caregivers. Parents must therefore plan for the future of their children when they are no longer able to provide care. The average age of death for people with developmental disabilities has become equal to the average age of death of people without disabilities. Excluding people with severe and multiple disabilities and Down syndrome, life expectancy is similar to the general population. As compared to 30 years ago, we now have more middle- and old-age individuals with ID/DD (Coppus, 2013).

During the interviews, parents described the experience of coming to terms with their own mortality, with this acceptance leading them to the realization that they cannot be their child's caregiver forever and they need to plan for intervention strategies and possible placement decisions. The parents expressed that they did not want to have to make placement decisions in the background of a crisis or an emergent placement of their adult child with ID/DD. They worried about what was going to happen to their children in the future and wanted a safe environment where they will be well cared for and thrive. One parent stated, "But to me again the reason for my decision [placement] was because someday I'm gonna die. I'm older than her, so odds are I'm gonna die before her. I die before her, she loses—or me or my husband. You know. She loses her house, she loses her caretaker."

The parents' acceptance of their own mortality was a catalyst to identifying that PARENTS CANNOT BE CAREGIVERS FOREVER, and facilitated readiness for consideration of placement decision and exploration of placement options.

A secondary review of the literature examined a concept analysis by Mcleod-Sordjan (2014) that explored death preparedness. The findings from this study revealed that death preparedness leads to acceptance and/or awareness, resulting in the implementation of a plan. A person's level of death preparedness and awareness can be facilitated by communication with a healthcare professional.

This concept analysis focused on analysis of the concept of death preparedness and supported the findings from the present research. In order for parents to be ready to make a residential decision placement for their adult children with ID/DD, it is necessary for them to identify their own mortality. Parent participants discussed their need to develop a plan for the future of their adult children with ID/DD when they are no longer here to care for them.

**Support system: Necessity of a support system in the decision-making process.**

Support systems exert a significant influence on parent caregivers' readiness to consider decisions regarding residential group home placement. In addition to the interdisciplinary healthcare team, particularly nurses, parent caregivers reported that strong extended family network and friends are a valuable source of support. These various resources provide the opportunity to gain knowledge and share information. Parents reported that what was vital for the caring and future planning for their adult child with ID/DD were day programs, transportation services, respite care, and support groups.

Most parents stated they felt ready to discuss placement options when they received adequate information from the interdisciplinary healthcare team, including nurses, as well as

through participation in support groups and family advocacy. However, as discovered in the research, parents frequently needed to be their own advocates, seeking out information. This depth and breadth of information was reassuring to them. Their self-identified feelings that **PARENTS CANNOT BE CAREGIVERS FOREVER** assisted them in being ready to consider placement decisions.

However, many of the parents reported that minimal formal support or direction was offered or provided to them regarding options and services available for their child. Other parents described a lack of support and “feeling on their own.” This resulted in the necessity for parents to be their own advocates and to seek out information regarding available options and services, as has been described by Bishop et al. (2015). The authors provided guidelines for dementia-related health advocacy for adults with intellectual disabilities and dementia developed by a national task force.

Parents spoke about the difficulties they had in finding appropriate services to meet both their own and their children’s needs. Parents without the necessary or accurate information perceived that residential-based service systems could not meet their needs. Many parents looked for validity to what they were experiencing and feeling, and for reassurance that their feelings of stress and being overwhelmed were appropriate and to be expected when being caregivers for this vulnerable population. They often sought out friends who were also parents of children with disabilities, as they were an invaluable source of companionship and understanding. Many looked for reassurance and approval that they should not feel guilty about seeking residential group home placement. Some parents who decided on residential placement spoke about the great sense of sadness and loss they experienced, as well as feelings of guilt and failure when they felt they could no longer care for their adult child with ID/DD. Some

described it as the hardest decision they had to make (Alborz, 2003; Mirfin-Veitch et al., 2003). These findings confirm those previously identified by Alborz (2003) and Mirfin-Veitch et al. (2003) as a very difficult decision.

People with developmental disabilities need lifelong supports. It is therefore important that parent caregivers plan for the future for their adult children with ID/DD. They must plan for long-term care for after the parents are deceased, incapacitated, or otherwise unable to perform care. Parents reported that when they were provided the necessary support and sharing of information, many were able to explore the options available and feel comfortable with the realization that PARENTS CANNOT BE CAREGIVERS FOREVER. The parents described a level of comfort with the information, education, instruction, and knowledge they received, and their confidence with the interdisciplinary healthcare team enabled them to experience a sense of acceptance of their inability to care for their child forever. It is at that point that parents reported the perceived *readiness* to make placement decisions.

### **Contextual Element of Time in Decision Making**

The current literature does not identify or clearly distinguish *how* parent caregivers make the decision about residential group home placement. This Grounded Theory research provides an understanding of how parents make the decision regarding residential group home placement for their adult child with ID/DD and the shared decision-making model for the interdisciplinary healthcare team, particularly nurses, and parent caregivers.

The research found the contextual element of time contributed to and impacted the placement decision process. It is the contextual element of time during which all decisions were made. The word “time” recurred throughout the data explaining that it is a context of time during which parents recognized the need for smaller decisions along the way, leading to the

“big” decision of residential group home placement. Parents are required to make decisions throughout a lifetime of caring for the child with ID/DD. These decisions throughout the lifetime of a child with ID/DD can contribute to and impact the placement decision process.

With this increased knowledge, and by linking professional caregiving needs to where the parents are over “time,” members of the interdisciplinary healthcare team, particularly nurses, can provide support and create interventions or strategies that can potentially have a positive influence on a parent’s decision-making abilities.

### **Shared Decision Making and Residential Group Home Placement**

A model that helps bring patients (parents) into the decision-making process is shared decision making (SDM). Effective decision making includes the best evidence and specific patient considerations, as well as valuable information provided to the patient and family prior to the decision making. The utilization of effective decision making encompasses explanations about the patient’s medical condition as well as the benefits and risks of various treatment options (Godolphin et al., 2001).

Shared decision making should be a collaborative process between the interdisciplinary team and parents. The parents and the interdisciplinary team should bring their preferences and information to the decision process. Together, parents and the interdisciplinary team should consider all the information and reach the decision.

This research discovered that the SDM models—a) shared rational deliberative patient choice; b) shared rational deliberative paternalism; c) shared rational deliberative joint decision model; d) professional driven best interest compromise model; and e) informed shared decision making—were not utilized with parents who participated in this study during the residential group home placement decision process for their adult child with ID/DD.

However, the research indicated that parents may benefit from proactive and systematic SDM for residential group home placement decisions. The interdisciplinary healthcare team and particularly nurses should have an integral role in supporting parents of adult children with ID/DD in the residential placement decision-making process.

### **Watson's Caring Science Theory**

Jean Watson's Caring Science is applicable when caring for the vulnerable population of persons with intellectual/developmental disabilities. A theory based on caring recognizes the importance of the relationship between the nurse and patient, with an emphasis on the nurse's role in providing support through the means of human caring. Watson's caring science theory is a philosophy and science of caring along with humanistic nursing. The major elements of her theory are the *caritas* processes, the transpersonal caring relationship, and the caring occasion/caring moment. The holistic outlook addresses the impact and importance of altruism, sensitivity, trust, and interpersonal skills. Watson's (2007) theory is centered on the concept that "Humans cannot be treated as objects and that humans cannot be separated from self, others, nature and the larger universe." The theory's assumptions address the concept of vulnerability, a trait inherent in the person with ID/DD.

The experience of the parent caregivers when placing their adult child with ID/DD into a residential group home could be a more tolerable and pleasant experience incorporating Watson's science of caring in the decision-making process.

Watson's *caritas* processes could be applied to the parent caregiver experience to better understand what caring is and what the role of the caregiver is in the caring process. Watson's *caritas* processes are interventions that affirm the subjectivity of the persons and lead to positive change for the welfare of the other, but also allow the nurse to benefit through personal and



professional growth. Watson's caritas processes could help ensure that those involved in the decision process are providing the ID/DD person with optimal care. The caritas processes that guide a nurse's care can also guide the parent caregiver's care (Tomey & Alligood, 1998). The parent caregiver's and the nurse's utilization of the Watson's theory will not be the same; however, the goals are the same, to: a) provide the best quality of life, b) maintain most favorable health, c) promote independence, and d) make the optimal decision for residential group home placement for the person with ID/DD.

Nurses involved in the decision-making process for placement of the adult child with ID/DD into a residential group home could apply Watson's caring science theory. Watson's theory allows nurses to better understand culture and encourage the development of holistic nursing practice by identifying themselves through the experiences of others (Tomey & Alligood, 1998).

According to Watson (2007), a caring occasion is the moment when the nurse and the patient come together in such a way that an occasion for human caring is created. Both persons, with their unique phenomenal fields, have the possibility to come together in a human-to-human transaction. Nurses need to be aware of their own consciousness and authentic presence of being in a caring moment with the parents.

Watson proposed the 10 carative factors based on the human care process. The carative factors are those used by a nurse when providing care to the patient and when assisting the patient to maintain or reach health, or to die a peaceful death. The 10 carative factors are interventions that permit the nurse to grow and benefit while confirming subjectivity of the person. They lead to positive change for the welfare of the other. The nurse in Watson's theory achieves the ideals of caring by application of her carative factors (Watson, 1985). Watson is

one of the few nursing theorists who consider not only the person who is cared for, but also the caregiver. Promoting and applying these caring values in practice is essential for nurses' health and to finding meaning in nurses' work.

Watson's carative factors provide a guide for nursing actions. The first three carative factors form the "philosophical foundation" for Watson's science of caring. The remaining seven carative factors are based on that philosophical foundation. Watson's 10 carative factors are: a) forming a humanistic, altruistic system of the ideas; b) instilling faith-hope; c) cultivating sensitivity to one's self into others; d) developing helping-trust relationships; e) expressing positive and negative feelings; f) use in scientific problem-solving methods for decision-making; g) promoting interpersonal teaching-learning; h) providing an environment that supports, protects, and corrects mental, physical, sociocultural, and spiritual aspects; i) assisting with the gratification of human needs; and j) allowing for existential-phenomenological forces (Watson, 2005). Watson (1985) defined caring as "the moral ideal of nursing whereby the end is protection, enhancement, and protection of human dignity. Human caring involves values, a will and commitment to care, knowledge, caring actions, and consequences" (p. 29).

Over the years Watson's values and ideas have continued to evolve. In 2001, Watson transformed the 10 carative factors into *caritas processes*. The *caritas processes* include an aura of love and caring in addition to a spiritual dimension (see Appendix N). Watson translated her original carative factors into *caritas processes*. Bailey (2009) illustrated what differed in Watson's clinical *caritas* framework as compared to the carative factors. The *caritas* have a spiritual dimension and an overt evocation of love and caring that merge into a new paradigm that will continue in the future.

To understand the parent caregivers' role more fully in the decision-making process, Watson's 10 caritas were considered in the parent caregivers' experience. Watson (1985) defined caring as "Human caring involves values, a will and commitment to care, knowledge, caring actions, and consequences." The parent caregiver who assumes the role as decision maker for his or her adult child with ID/DD can also embrace aspects of Watson's caritas processes in an effort to make a decision regarding residential placement for the adult child with ID/DD.

**Summary of application of Watson's caritas.** The adult child with ID/DD is a member of a vulnerable population with unique, special needs and considerations. Living with and caring for a person with disabilities can have profound effects on the parent caregivers, which, in turn, can affect the health and well-being of both the caregiver and the person with disabilities. Many parents presume as their children age that they will eventually live away from the family home. For the parent caregivers of the person with ID/DD, this expectation may be more difficult to realize. The need for care and the support necessary may be long term and ongoing. The decision for residential group home placement is difficult and complex. Many programs and organizations can provide resources for families and the disabled person. Parents of adult children with disabilities are growing in number and increasing in age due to advances in health and social care. Throughout the life of the ID/DD person lacking cognitive ability, parent caregivers often make decisions about their welfare and particularly their living arrangements. Finding future living accommodations for this group of persons with disabilities is a priority. The need for decision making in this vulnerable population will become evident when the family is no longer able to provide care at home for their loved one with ID/DD. This may be a result of numerous factors, including aging parents, failing health of the caregiver, and financial or physical inability to provide care. The toll on the family dynamics as well as marital

relationships from the many years of caring for their loved one in the family home may result in the need for the decision to be made for residential group home placement.

The implementation of Watson's science of caring could be applied to guide the parent caregivers through the decision-making process. Utilization of the Watson's theory can guide nurses and caregivers both prior to and during the decision process. Watson's work can be used to guide and improve practice by providing the nurse with the most satisfying aspects of practice, and also provide the person with ID/DD and their parent caregivers with the holistic care necessary for human growth and development. Watson's theory clearly encompasses the theories of stress, development, communication, teaching-learning, humanistic psychology, and existential phenomenology that provide the foundation for the science of caring (Cara & O'Reilly, 2008) and is vital in caring for a vulnerable population including persons with ID/DD and their families. In addition to providing the quality of care that the person with ID/DD ought to receive, another positive aspect of the application of Watson's theory is that it provides a foundational meaning to caring for which many nurses enter the profession.

Although Watson's emphasis on caring is not unique, the strength of her focus on the embodied spirit is. Watson set a high standard for nurses to follow and bring into their work a number of important concepts. Watson's carative approach embodies spiritual concepts along with the philosophical concepts of existentialism and phenomenology (Cohen, 1991). This deep meaning and approach are more abstract than some nurses wish to pursue. According to Cara and O'Reilly (2008), Watson's theory advocates for the development of nursing behaviors not currently in practice, which can be difficult for some nurses to conceptualize. However, Watson's theory continues to evolve and to attract the attention of many, as nurses are drawn to the holistic nature of the theory (Cara & O'Reilly, 2008).

Watson's theory places the adult child with ID/DD in the context of the family, the community, and the culture. Additionally, it places the client as the focus of practice. The caring component of the theory could better help guide the parent caregivers in making the decision and adjust to the placement of their adult child with ID/DD in a residential group home setting.

Watson's Caring Science theory could assist the family of the adult child with ID/DD through the difficult decision process, and could help determine at what point in the life of the person with ID/DD these discussions are most appropriate to begin. Because of the holistic, loving, caring, spiritual values, and deep meaning that emanates from the theory, the unique vulnerable population of the ID/DD persons and their families would be well supported by Watson's theory.

### **Limitations of the Study**

Several limitations were identified with regard to the approach used in this qualitative research study. Grounded Theory research can limit the ability to make broader generalizations due to the use of a purposeful, theoretical sample, instead of a random sampling of participants. However, Grounded Theory methodology was purposefully chosen to seek a deeper understanding of how parent caregivers make the decision for residential group home placement for their adult child with ID/DD. Interviews were conducted to seek a symbolic, descriptive explanation of what is occurring from each parent's perspective.

Another limitation of the study included a relatively small parent sample size and predominately female participants. The participants chosen were purposeful and specific (N = 15). It may be beneficial in future studies to include more fathers or even other family caregivers (siblings, grandparents, aunts, uncles) and not exclusively the parents.

An additional limitation was that participants were chosen from a specific geographical location. Although maximum variation sampling was used, the sample resulted in a relatively homogeneous group with regard to socioeconomic level and ethnicity. Due to the homogeneity of the study, it would be difficult to clearly recognize any cultural influences with regard to caregiving and decision placement in this study. Future studies may benefit from a more diverse group of study participants to examine the experience of different ethnicities and cultural backgrounds to better determine if any cultural influences are present in placement decision.

Further limitations occur with the recognition that the study represents a “snapshot in time” when describing and explaining how parents make residential group home placement decisions for their adult child with ID/DD. The research design was a retrospective recall and did not permit a longitudinal or prospective examination of the parent caregiver’s decision-making process over time. It may be necessary in future studies to include repeated contact with the parent participants over a period of time to elucidate the experiences that are not limited to a snapshot in time (Penrod & Dellasega, 1998).

### **Office for People With Developmental Disabilities: Front Door**

Furthermore, decision placement for almost all of the parents represented in the study had occurred before the impact of a new model of care, and the effects it potentially has on the decision to place a child. In 2013 a “front door” philosophy was initiated by OPWDD and requires that all individuals who are in need of services through the Home and Community Based Services (HCBS) waiver must first contact their local Developmental Disabilities Regional Office (DDRO), also known as the “front door.” DDRO staff complete eligibility assessments and inform the individual and their families of the services that are available to them.

The services include but are not limited to Medicaid Service Coordination (MSC), family and support services, Individualized Residential Alternatives (IRAs), respite services, day habilitation, and supportive employment services (OPWDD, 2015).

With the inception of the “front door” self-directed services and enhanced community and family supports, a whole cadre of options is available to families that were not available and not offered to families prior to 2013. The recent 2013 initiative by OPWDD of the “front door” policy was to help guide individuals and their families through eligibility determination and build on the philosophy of self-determination and person-centered planning. Additionally, the purpose was to improve the way people learn about and access available services. This prompts the question: would the decision-making process of the participants in this study be different if it was made today?

In addition, in order to better enable the researcher to fully understand the phenomenon under study, the initial plan was to interview several parents who had decided against residential group home placement. However, only one parent who decided against placement was interviewed for the research study. The researcher had difficulty in obtaining the participants who met those criteria. The limitations may be addressed in future studies by recruiting more parents who have decided against residential placement.

Despite its limitations, this study has important implications for parents making residential group home placement decisions for their adult child with ID/DD. This study also provides greater depth into understanding the decision-making process of parent caregivers and for understanding the needs of parents of children with developmental disabilities.

### **Implications for Practice**

Grounded Theory research in this area provided an understanding of the phenomenon that helped to identify the most appropriate point in the life of a person with ID/DD for healthcare professionals, particularly nurses, to begin residential group home placement discussions with parents. In addition, the research identified the implication for practice and an understanding by health and social services professionals about the possible usefulness of offering transitional support groups for parents. Furthermore, research in this area provided an understanding of the need for the interdisciplinary healthcare team, particularly nurses, to implement and utilize SDM to better support parents through the decision-making process for residential group home placement. Greater understanding and clarity of the phenomenon will help create targeted interventions or strategies for nurses, clinicians, and the interdisciplinary healthcare team for this unique population. The creation of targeted interventions or strategies can potentially influence parents' decision-making abilities positively and offer professionals direction for further research. This increase in knowledge for nurses can help in planning better supportive shared decision intervention for parents faced with making the decision for possible residential group home placement for their adult child with ID/DD.

### **Implications for Future Research**

The area of research suggests that it could have wider applicability to other disciplines, such as social sciences and medicine, as well as point to further areas of study to explore the phenomenon in greater detail. The findings have the potential for national dissemination via publications and presentations to inform nursing in general. Additionally, the study findings can influence health policy by future policy development that recognizes the need to support those skills to achieve a positive outcome for the parent caregivers, as well as the adult child with



ID/DD they care for, within the constraints of the current healthcare system. Furthermore, this area of research suggests there could be further areas of qualitative and quantitative study to explore the phenomenon in greater detail.

### **Summary**

Many people with developmental disabilities have grown up at home with their families and lived as adults in our communities. Yet only in the last 20 years has there been a sustained movement to assist families to meet some of the additional demands that come with raising a child with a developmental disability. Through this investigative inquiry, it was determined that long-term residential group home placement settings are one of the services sought out by families. When families raising a child with developmental disabilities, figuring out options and making decisions to make their hopes and dreams a reality is often much more complex and requires a great deal more effort and planning.

This Grounded Theory study generation of a substantive theory described and explained the decision-making process that parent caregivers embark upon when considering residential group home placement for their adult child with ID/DD. A 2008 report on the State of the States in Developmental Disabilities, produced by the Coleman Institute for Cognitive Disabilities at the University of Colorado, noted that “the nation’s overall residential system capacity has doubled since 1987, with an annual growth rate of 5% per year.” It is evident that this decision is one that most parent caregivers face for their adult child with ID/DD. Just as each adult child with ID/DD is unique in his or her own way, so too are parents and families. Parents have different cultures, backgrounds, beliefs, and values. Therefore, the way each family approaches the decision to consider residential placement can vary substantially.

The research revealed that it was only when a parent caregiver recognized and acknowledged that PARENTS CANNOT BE CAREGIVERS FOREVER, for both themselves and the adult child with ID/DD, that parents were *ready* to make residential group home placement decisions. The development of this substantive theory serves to help close the gap in nursing literature while offering substantial contributions to the health and human services industry.

## References

- Alborz, A. (2003). Transitions: Placing a son or daughter with intellectual disability and challenging behaviour in alternative residential provision. *Journal of Applied Research in Intellectual Disabilities, 16*, 75-88.
- American Association on Intellectual and Developmental Disabilities. (2013). Retrieved from <http://www.aaidd.org>
- Anderson, S., Coli, R., Daly, I., Kichula, E., Rork, M., Volpi, S., Ekstein, J., & Rubin, B. (2001). Familial dysautonomia is caused by mutations of the IKAP gene. *American Journal of Human Genetics, 68*(3), 753-758.
- Avidan, A., & Kaplish, N. (2010). The parasomnias: Epidemiology, clinical features, and diagnostic approach. *Clinical Chest Medicine, 31*, 353-370.
- Bailey, D. (2009). Caring defined: A comparison and analysis. *International Journal for Human Caring, 13*(1), 16-31.
- Beach, S., Schulz, R., Yee, J., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15*(2), 259-261.
- Beauchamp, T. L., & Childress, J. F. (1994). *Principles of biomedical ethics* (4th ed.). New York, NY: Oxford University Press.
- Bishop, K., Hogan, M., Janicki, M., Keller, S., Luchino, R., Mughal, D., ... Wolfson, S. (2015). Guidelines for dementia related health advocacy for adults with intellectual disabilities and dementia: National task group on intellectual disabilities and dementia practices. *Intellectual and Developmental Disabilities, 53*(1), 2-29.
- Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E., & Montgomery, P. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology Series A: Biological Science and Medical Science, 57*, 470-472.
- Bittles, A., Bower, C. Hussain, R., & Glasson, E. (2007). The four ages of Down syndrome. *European Journal of Public Health, 17*, 221-225.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley, CA: University of California Press.
- Boyles, C., Baily, P., & Mossey, S. (2008). Representations of disability in nursing and healthcare literature: An integrative review. *Journal of Advanced Nursing, 62*(4), 428-437.

- Braddock, D., Hemp, R., & Rizzolo, M. C. (2008). *The state of the states in developmental disabilities: 2008*. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.
- Briggs, A. (2014). Primary care of a child with Rett Syndrome. *Journal of the American Association of Nurse Practitioners*, 26(9), 471-480.
- Brody, H. (2007). Transparency and self-censorship in shared decision-making. *American Journal of Bioethics*, 7(July), 44-46.
- Bromley, B., & Blacher, J. (1991). Parental reasons for out-of-home placement of children with severe handicaps. *Mental Retardation*, 29, 275-280.
- Bruns, D., & Foerster, K. (2011). We've been through it all together: Supports for parents with children with rare trisomy conditions. *Journal of Intellectual Disability Research*, 55(4), 361-369.
- Cara, C., & O'Reilly, L. (2008). Embracing Jean Watson's theory of human caring through a reflective practice within a clinical situation. *Rech Soins Infirm*, 95, 37-45.
- Carr, J. (1975). *Young children with Down's Syndrome*. London, UK: Butterworth.
- Carroll, M., Kenny, A., Patwari, P., Ramirez, J., & Weese-Mayer, D. (2012). Respiratory and cardiovascular indicators of autonomic nervous system deregulation in familial dysautonomia. *Pediatric Pulmonology*, 47(7), 682-691.
- Casarett, D., Crowley, R., Stevenson, C., Xie, S., & Teno, J. (2005). Making difficult decisions about hospice enrollment: What patients and families want to know? *Journal of the American Geriatrics Society*, 53(2), 249-254.
- Centers for Disease Control and Prevention (CDC). (2013). National Center on Birth Defects and Developmental Disabilities. Retrieved from <http://www.cdc.gov/ncbddd/dd/ddcp.htm>
- Centers for Disease Control and Prevention (CDC). (2015). 10 things to know about new autism data. Retrieved from <http://www.cdc.gov/features/dsautismdata/index.html>
- Chan, J., Sigafos, J., Watego, N., & Potter, G. (2001). Adults with intellectual disability in long-term respite care: A qualitative study. *Journal of Intellectual and Developmental Disability*, 26(4), 339-344.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science and Medicine*, 44, 681-692.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

- Cheung, N. (2013). Defining intellectual disability and establishing a standard of proof: Suggestions for a national model standard. *Health Matrix*, 23(1), 318-351.
- Chiu, H. C., Ada, L., Butler, J., & Coulson, S. (2011). Characteristics of associated reactions in people with hemiplegic cerebral palsy. *Physiotherapy Research International*, 16, 125-132.
- Cohen, J. (1991). Two portraits of caring: A comparison of the artists, Leininger and Watson. *Journal of Advanced Nursing*, 16, 899-909.
- Coppus, A. (2013). People with intellectual disabilities: What do we know about adulthood and life expectancy? *Developmental Disabilities Research*, 18, 6-16.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among the five traditions*. Thousand Oaks, CA: Sage.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), 1476-1484.
- Davys, D., & Haigh, C. (2007). Older parents of people who have learning disability: Perceptions of future accommodation needs. *British Journal of Learning Disabilities*, 36, 66-72.
- Degeneffe, C. E., & Terciano, J. (2011). Rosa's law and the language of disability: Implications for rehabilitation counseling. *Rehabilitation Research, Policy, and Education*, 25(3&4), 163-172.
- Dellasega, C., & Mastrian, K. (1995). The process and consequences of institutionalizing an elder. *Western Journal of Nursing Research*, 17(2), 123-140.
- Depositario-Cabacar, D. F., & Zelleke, T. G. (2010). Treatment of epilepsy in children with developmental disabilities. *Developmental Disabilities Research Reviews*, 16, 239-247.
- Developmental Disabilities Nurses Association. (2015). Retrieved from <http://www.ddna.org>
- Dillenburger, K., & McKerr, L. (2009). 40 years is an awful long time: Parents caring for adult sons and daughters with disabilities. *Behavior and Social Issues*, 18, 1-20.
- Dodge, N. N. (2008). Cerebral palsy: Medical aspects. *Pediatric Clinical North America*, 55(5), 1189-1207.
- Elwyn, G., Edwards, A., & Kinnersley, P. (1999). Shared decision-making in primary care: The neglected second half of the consultation. *British Journal of General Practice*, 477-482.

- Falzer, P. R., & Garman, M. D. (2009). A conditional model of evidence-based decision making. *Journal of Evaluation in Clinical Practice, 15*, 1142-1151.
- Family Caregiver Alliance: National Center on Caregiving. (2013). Retrieved from <http://www.caregiver.org/caregiver/jsp/home.jsp>
- Family Residences and Essential Enterprises, Inc. (2013). Retrieved from <http://www.familyres.org>
- Frank, R. K. (2009). Shared decision-making and its role in end of life care. *British Journal of Nursing, 18*(10), 612-618.
- Fujiura, G. T. (2013). The demarcation of intellectual disability. *Intellectual and Developmental Disabilities, 51*(2), 83-85.
- Garner, B. A. (2009). *Blacks law dictionary standard* (9th ed.). Eagan, MN: West Group.
- Gaus, V. (2011). *Living well on the spectrum*. New York, NY: Guilford.
- Gelling, L. (2011). The complexities of using grounded theory. *Nurse Researcher, 18*(4), 4-5.
- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. (2007). Doing formal theory: A proposal. *The Sage handbook of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Godolphin, W., Towle, A., & McKendry, R. (2001). Evaluation of the quality of patient information to support informed shared decision-making. *Health Expectations, 4*, 235-242.
- Grandin, T. (2013). *The autistic brain: Thinking across the spectrum*. New York, NY: Houghton Mifflin Harcourt.
- Guba, E., & Lincoln, Y. (1981). *Effective evaluation*. San Francisco, CA: Jossey-Bass.
- Hain, D., & Sandy, D., (2013). Partners in care: Patient empowerment through shared decision-making. *Nephrology Nursing Journal, 40*(2), 153-157.
- Hedov, G., Anneren, G., & Wikblad, K. (2000). Self-perceived health in Swedish parents of children with Down's syndrome. *Quality of Life Research, 9*(4), 415-422.

- Hewitt, A., Lightfoot, E., Bogenschutz, M., McCormick, K., Sedlezky, L., & Doljanac, R. (2010). Parental caregivers' desires for lifetime assistance planning for future supports for their children with intellectual and developmental disabilities. *Journal of Family Social Work, 13*, 420-434.
- Hook, M. L. (2006). Partnering with patients-a concept ready for action. *Journal of Advanced Nursing, 56*(2), 133-143.
- Hubert, J. (2010). My heart is always where he is: Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home. *British Journal of Learning Disabilities, 39*, 216-224.
- Hunter, A., Murphy, K., Grealish, A., Casey, D., & Keady, J. (2011). Navigating the grounded theory terrain: Part 1. *Nurse Researcher, 18*(4), 6-10.
- Janicki, M., Dalton, A., Henderson, C., & Davidson, P. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation, 21*, 284-294.
- Janicki, M. P., & Wisniewski, H. M. (Eds.). (1985). *Aging and developmental disabilities issues and approaches*. Baltimore, MD: Brookes.
- Katapodi, M. C., Munro, M. L., Pierce, P. F., & Williams, R. A. (2011). Psychometric testing of the decisional conflict scale. *Nursing Research, 60*(6), 368-377.
- Kellet, U. (1999). Transitions in care: Family carers' experience of nursing home placement. *Journal of Advanced Nursing, 29*(6), 1474-1481.
- Kelly, M., Tuli, S., Stern, M., & Giordano, B. (2015). Brothers with Smith-Lemli-Optiz Syndrome. *Journal of Pediatric Health Care, 29*(1), 97-103.
- Krigger, K. W. (2006). Cerebral palsy: An overview. *American Family Physician, 73*(1), 91-100.
- Lakin, K. C., Larson, S., Salmi, P., & Scott, N. (2009). Residential services for persons with developmental disabilities: Status and trends through 2008. Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.
- Lakin, K. C., Hill, B. K., & Bruininks, R. H. (1988). Trends and issues in the growth community residential services. In M. P. Janicki, M. W. Krauss, & M. M. Seltzer (Eds.), *Community residences for persons with developmental disabilities: Here to stay* (pp. 25-42). Baltimore, MD: Paul H. Brookes.
- Landsman, L. (2014). Are children with Prader Willi syndrome at higher risk for anesthetic complications? *Pediatric Anesthesia, 24*(4), 457-459.

- Licqurish, S. (2011). Applying a contemporary grounded theory methodology. *Nurse Researcher*, 18(4), 11-16.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage.
- Llewellyn, G., Dunn, P., Fante, M., Turnbull, L., & Grace, R. (1999). Family factors influencing out-of-home placement decisions. *Journal of Intellectual Disability Research*, 43(3), 219-233.
- Lundh, U., Sandberg, J., & Nolan, M. (2000). 'I don't have any other choice': Spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing*, 32(5), 1178-1186.
- McDonald, L., Owen, M., & McDonald, S. (1993). Quality care in residential placement for children and youth with developmental disabilities. *Behavioral Residential Treatment*, 8, 187-202.
- McLeod-Sordjan, R. (2014). Death preparedness: A concept analysis. *Journal of Advanced Nursing*, 70(5), 1008-1009.
- Merriam-Webster online dictionary*. (2013). Merriam-Webster Inc. Retrieved from <http://merriam-webster.com>
- Mirfin-Veitch, B., Bray, A., & Ross, N. (2003). "It was the hardest and most painful decision of my life!": Seeking permanent out-of-home placement for sons and daughters with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 28(2), 99-111.
- Morse, J. M. (1991). On the evaluation of qualitative proposals. *Qualitative Health Research*, 1, 147-151.
- Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220-235). Thousand Oaks, CA: Sage.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13-22.
- Morton, G. V. (2011). Why do children with Down Syndrome have subnormal vision? *American Orthoptic Journal*, 61, 60-70.
- Moulton, B., & King, J. (2010, Spring). Aligning ethics with medical decision-making: The quest for informed patient choice. *Journal of Law, Medicine and Ethics*, 85-97.



- Mullen, P. D., Dacey-Allen, J., Glanz, K., Fernandez, M. E., Bowen, D. J., Pruitt, S. L., ... Pignone, M. (2006). Measures used in studies of informed decision making about cancer screening: A systematic review. *Annals of Behavioral Medicine, 32*(3), 188-201.
- National Association for Down Syndrome. (2013). Retrieved from <http://nads.org>
- National Guardianship Association. (2013). Retrieved from <http://www.guardianship.org>
- National Institutes of Health. (2015). Retrieved from <http://www.nih.gov/>
- National Institute of Neurological Disorders and Stroke. (2013). Epilepsy. Retrieved from <http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>
- New York Department of Mental Hygiene. (2013). N.Y. MHY. Law § 1.03: NY Code - Section 1.03: Definitions. *Findlaw*. NY MHY Law, n.d. Retrieved from <http://codes.lp.findlaw.com/nycode/MHY/A/1/1.03>
- Nieswiadomy, R. (1998). Caregivers' experiences in making placement decisions. *Western Journal of Nursing Research, 20*(6), 706-730.
- O'Connor, A. M. (1995). Validation of decisional conflict scale. *Medical Decision Making, 15*, 25-30.
- O'Connor, A. M. (2002). *User manual: Decision Self-Efficacy Scale*. Available from [www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid).
- O'Connor, A. M., Tugwell, P., & Wells, G. A. (1998). A decision aid for women considering hormone therapy after menopause: Decision support framework and evaluation. *Patient Education and Counseling, 33*, 267-279.
- Office for People With Developmental Disabilities. (2013). Retrieved from <http://www.lifssac.com/3.html>
- Office for People With Developmental Disabilities. (2015). Retrieved from [http://www3.opwdd.ny.gov/wp/images/intro\\_to\\_pcp\\_handouts.pdf](http://www3.opwdd.ny.gov/wp/images/intro_to_pcp_handouts.pdf)
- Olsen-Roper, S., & Jackson, J. (2007). The ambiguities of out-of-home care: Children with severe or profound disabilities. *Family Relations, 56*, 147-161.
- Osório, A., Sampaio, A., Regueiro, R. M., Heinze, E. G., Carracedo, Á., & Prieto, M. F. (2015). Autism spectrum symptoms in Smith-Magenis Syndrome and Williams Syndrome: Comparisons and contrasts. *International Journal of Developmental Disabilities, 61*(1), 49-55.
- Parish, S., & Lutwick, Z. (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work, 50*(4), 345-354.

- Pastor, D. K. (2008). Decision making by elderly community dwelling spousal caregivers about long-term care placements for their partners with Alzheimer's disease: Seeing the changing reality. (Doctoral dissertation). Retrieved from Proquest Information and Learning Company. (UMI No. 3290525).
- Pastor, D., & Vogel, B. (2011). Supporting community caregiving for a spouse with dementia: Research with implications for practice. *Home Healthcare Nurse, 29*(7), 443-450.
- Patti, P., Amble, K., & Flory, M. (2010). Placement, relocation and end of life issues in aging adults with and without Down's Syndrome: A retrospective study. *Journal of Intellectual Disability Research, 54*(6), 538-546.
- Penrod, J., & Dellasega, C. (1998). Caregivers' experiences in making placement decisions. *Western Journal of Nursing Research, 20*(6), 706-730.
- Polit, D., & Hungler, B. (1997). *Essentials of nursing research, methods, appraisal, utilization*. (4th ed.). Philadelphia, PA: Lippincott.
- Prouty, R. W., Alba, K., & Lakin, K. C. (Eds.). (2008). Residential services for persons with developmental disabilities: Status and trends through 2007. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living/Institute on Community Integration.
- Qualitative Research Software: QRS International. (2013). Retrieved from <http://qsrinternational.com>
- Raina, P., O'Donnell, M., Rosenbaum, P., & Brehaut, J. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*(6), 626.
- Rodgers, B. L. (1989). Concepts, analysis, and the development of nursing knowledge: The evolutionary approach. *Journal of Advanced Nursing, 14*, 330-335.
- Rodgers, B. L., & Knafl, K. A. (Eds.). (2000). *Concept development in nursing: Foundations, techniques, and applications* (2nd ed.). Philadelphia, PA: Saunders.
- Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Ryan, A., & Scullion, H. (2000). Nursing home placement: An exploration of the experience of carers. *Journal of Advanced Nursing, 32*(5), 1187-1195.
- Sandman, L., & Munthe, C. (2010). Shared decision making, paternalism and patient choice. *Health Care Analysis, 18*, 60-84.

- Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association*, 282, 2215-2219.
- Slaugenhaupt, S., & Gusella, J. (2002). Familial dysautonomia. *Current Opinion in Genetics and Development*, 12(3), 307-311.
- Smith, G., Fullmer, E., & Tobin, S. (1994). Living outside the system: An exploration of families who do not use day programs. In M. Seltzer, M. Krauss, & M. Janicki (Eds.), *Life course perspectives on adulthood and old age* (pp. 1-38). Washington, DC: American Association on Mental Retardation.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.
- Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 273-285). London, UK: Sage.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing Grounded Theory* (2nd ed.). Newbury Park, CA: Sage.
- Sugarman, J. (2003). Informed consent, shared decision-making, and complementary and alternative medicine. *Journal of Law, Medicine and Ethics*, 31, 247-250.
- Tadema, A., & Vlaskamp, C. (2009). The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities*, 38, 41-48.
- Tingey, C. (1988). *Down syndrome: A resource handbook*. Providence, RI: College Hill Press.
- Tomey, A., & Alligood, M. (1998). *Nursing theorists and their work* (4th ed.). St. Louis, MO: Mosby.
- Towle, A., & Godolphin, W. (1999). Framework for teaching and learning informed shared decision making. *British Medical Journal*, 319, 766-771.
- Towle, A., Godolphin, W., Grams, G., & Lamarre, A. (2006). Putting informed and shared decision making into practice. *Health Expectations*, 9, 321-332.
- United Cerebral Palsy. (2013). Cerebral palsy: Facts and figures. Washington, DC. Retrieved from [http://www.ucp.org/ucp\\_channel.doc.cfm/1/11/10427/10427-10427/447](http://www.ucp.org/ucp_channel.doc.cfm/1/11/10427/10427-10427/447)
- Walker, L. O., & Avant, K. C. (2005). *Strategies for theory construction in nursing* (4th ed.). Upper Saddle River, NJ: Pearson Prentice-Hall.

- Wang, S. (2011). Nursing home placement of older parents: An exploration of adult children's roles and responsibilities. *Contemporary Nurse*, 37(2), 197-203.
- Watson, J. (1985). *Nursing: Human science and human care: A theory of nursing*. Norwalk, CT: Appleton-Century-Crofts.
- Watson, J. (2005). *Caring science as sacred science*. Philadelphia, PA: F.A. Davis.
- Watson, J. (2007). *Human science and human care a theory of nursing*. Sudbury, MA: Jones and Bartlett.
- Weston, W. W. (2001). Informed and shared-decision making: The crux of patient-centered care. *JAMC*, 165(4), 438-439.
- Whitney, S. N., McGuire, A. L., & McCullough, L. B. (2004). A typology of shared decision-making, informed consent, and simple consent. *Annals of Internal Medicine*, 140(1), 54-59.
- Wills, C. E., & Holmes-Rovner, M. (2003). Patient comprehension of information for shared treatment decision making: State of the art and future directions. *Patient Education and Counseling*, 50(3), 285-290.
- Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Mental Retardation*, 43(1), 1-10.
- Yoo, J., & Hunter, J. (2013). Imaging spectrum of pediatric corpus callosal pathology: A pictorial review. *Journal of Neuroimaging*, 22(2), 281-282.

## Appendix A: Consent

**Molloy College**  
**1000 Hempstead Avenue**  
**Rockville Centre, New York**  
**Nursing Department: PhD in Nursing**

### Participant Consent Form

**Purpose:**

The purpose of this interview is to examine how parents made the decision about residential group home placement for their adult child with intellectual/developmental disabilities?

**Procedure:**

If you agree to be in this interview, you will be asked to do the following:  
 Respond to questions about this area of interest during a digitally-recorded interview.  
 The interview will then be transcribed and all information will be de-identified.  
 The total time required to complete the interview should be approximately 60 minutes.

**Voluntary Nature of the Interview/Confidentiality:**

Your participation in this interview is entirely voluntary and you may refuse to complete the interview at any point during the discussion, or refuse to answer any questions with which you are uncomfortable. You may also stop at any time and ask the researcher any questions you may have. Your name will never be connected to your results or to your responses during the interview; instead, a number will be used for identification purposes. Information that would make it possible to identify you or any other participant will never be included in any sort of report. All data will be de-identified. The data will be accessible only to those working on the project. To protect your confidentiality, your name and any other identifying information about you will be removed from the transcript of your interview. This investigator, or another investigator, may wish to use the data obtained from your interview for a future secondary analysis to answer a new research question. You may contact the researcher for the results of the completed study.

**Contacts and Questions:**

At this time you may ask any questions you may have regarding this interview. If you have questions later, you may contact Laura A. Sardinia-Prager MSN, RN, CDDN, QDCP (Doctoral Candidate) at 516 849-8760 or e-mail at lprager@molloy.edu

**Statement of Consent:**

I have read the above information. I have asked any questions I had regarding the interview procedure and they have been answered to my satisfaction. I consent to participate in this interview.

Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

(please print)

Signature of Participant: \_\_\_\_\_

**Appendix B: Demographic Inventory****Requested Demographic Inventory:****Please fill in the blank or circle the appropriate answer**

1. Your age: \_\_\_\_\_
2. Your gender:
  - a. Male
  - b. Female
3. Do you belong to any racial/ethnic group? Please place a check next to the group with which you most identify:
  - a. White (non-Hispanic) \_\_\_\_\_
  - b. Black (non-Hispanic) \_\_\_\_\_
  - c. Hispanic \_\_\_\_\_
  - d. Asian \_\_\_\_\_
  - e. Native American \_\_\_\_\_
  - f. Pacific Islander \_\_\_\_\_
  - g. Other (Describe if more than one or other not listed)\_\_\_\_\_
4. What was your marital status when the decision regarding placement was made?:
  - a. Married
  - b. Single (never married)
  - c. Partner
  - d. Widow/Widower
  - e. Divorced
  - f. Separated
5. What is your marital status now?:
  - a. Married
  - b. Single (never married)
  - c. Partner
  - d. Widow/Widower
  - e. Divorced
  - f. Separated
6. Number of children in the family?: \_\_\_\_\_

7. What was the number of children living in the family home when the decision regarding placement was made?: \_\_\_\_\_
8. Your level of education completed:
- a. High School
  - b. Associate degree
  - c. Bachelor's degree
  - d. Master's degree or higher
  - e. Other \_\_\_\_\_
9. How many years did you/have you cared for your child at home?: \_\_\_\_\_
10. Do you work outside the home? \_\_\_\_\_
11. If applicable, when did you place your adult child into a residential group home?: (Please indicate the year of placement) \_\_\_\_\_
12. If your child was placed on a waiting list for placement what was the length of time (number of days, months, years) on the waiting list?: \_\_\_\_\_ or N/A \_\_\_\_\_
13. What is this child's placement in your family (birth order, please describe)? \_\_\_\_\_
14. How old was your child at the time of placement into the residential group home? \_\_\_\_\_
15. Was your child born with or acquired the problem as a result of trauma? (please describe)
- 

*Thank you for your participation!*

## Appendix C: Interview Guide

### INTERVIEW GUIDE

#### *A Grounded Theory Study of How Parents Made the Decision About Residential Group Home Placement for their Adult Child with Intellectual/Developmental Disabilities*

Open-ended script:

Hello, my name is Laura Sardinia-Prager. I am a doctoral student at Molloy College working on completion of my dissertation exploring the phenomenon of How Parents Made the Decision About Residential Group Home Placement for their Adult Child with Intellectual/Developmental Disabilities. Thank you for taking the time to meet with me and to participate in my study. I will be recording our conversation with a digital recorder that will be transcribed verbatim at a later date. I am looking forward to hearing and understanding your experience. Can you tell me about your decision experience regarding residential placement for your adult child with ID/DD.

In the event the participant requires further prompting the below questions with probes can be used by the interviewer to obtain additional information. Using Grounded Theory methodology the questions may need to be adjusted from one interview to the next to gain a rich in-depth understanding of the phenomenon.

Open-ended interview questions and probes:

1. Tell me what it was like for you when you learned of your child's diagnosis?

Probe: What did it mean to you?

Probe: How did that change over time?

Probe: What is the nature of your child's diagnosis? Medical conditions, physical conditions, psychological conditions?

2. Describe how you care for your child with ID/DD?

Probe: Who was the primary caregiver? If you were the primary caregiver, what was your experience in being the primary caregiver?

Probe: What was it like being the caregiver of an adult child with ID/DD?

Probe: Did you have anyone to assist you? Did you have support? Spouse? Family? Friends? Other parents?

Probe: Describe your daily routine?

Probe: Are you able to find any time for yourself? Find time for other family members?

Probe: If you have other children, what was this caregiving like in comparison?

3. Describe a specific experience or moment in time that resulted in you beginning to explore options for possible residential group home placement for your adult child?

Probe: Describe how you made the decision regarding residential group home placement?



Probe: What things in particular prompted you to seek options about placement? (i.e. was there a change in family relationships, finances, change in the needs of the adult child with ID/DD, change in your own physical health?)

4. How did you get assistance in making the decision regarding possible residential group home placement for your adult child with ID/DD?

Probe: What surprised you most about making the decision?

Probe: What was the response of your child to the possibility of placement?

Probe: What was your adult child's role in the decision process?

5. How did you know that it was, or was not the appropriate time to place your adult child with ID/DD in a residential group home?

Probe: Tell me about how your adult child may have participated in the decision?

Probe: What other options did you consider?

Probe: Were there obstacles to your decision-making?

Probe: How did you judge the quality of the care options?

6. How do you feel about your decision?

Probe: Describe to me your feelings of satisfaction with your decision?

Probe: In retrospect would you have done anything differently? If so, what?

7. What is your life like since your decision was made for your adult child with ID/DD regarding possible placement into a residential group home?

Probe: What is different for you now?

Probe: Can you share with me any positive/negative changes for you/family? for your adult child with ID/DD?

8. Is there anything else you would like to tell me about your decision regarding placement?

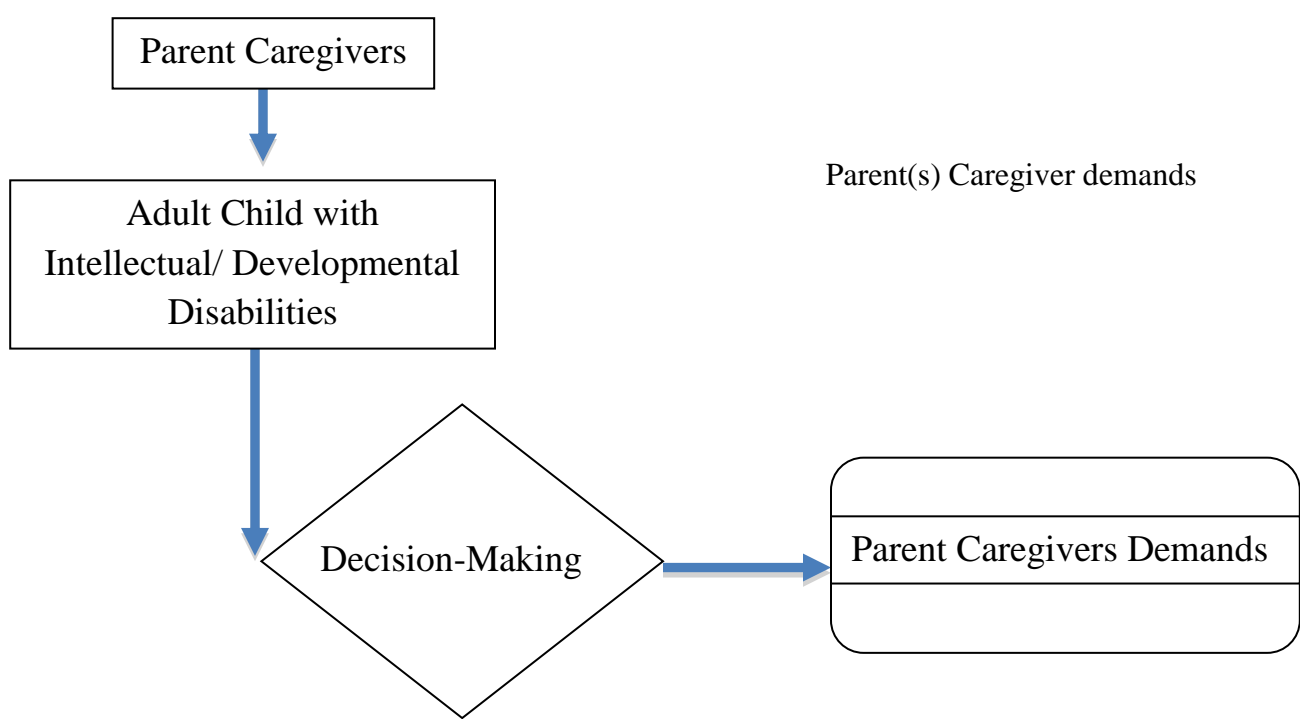
Probe: Please tell me what I need to know to understand your experience.

### Appendix D: Concept Map

#### Concept Map

#### Decision Making and Residential Group Home Placement

A Grounded Theory Study of How Parents Made the Decision About Residential Group Home Placement for their Adult Child with Intellectual/Developmental Disabilities?



## Appendix E: Study Recruitment Flyer

**Have You Recently Made a Decision Regarding Residential Group Home Placement for  
your Adult Child with Intellectual/Developmental Disabilities?**

*If so, you may be eligible to participate in a Nursing Research study being conducted by Laura Sardinia-Prager; doctoral candidate in the PhD in Nursing program at Molloy College.*

*I am exploring parent's decision-making experience regarding residential group home placement within the past 5 years of their adult child with ID/DD and would like to hear from you. Participants can include parents who have decided for or against residential group home placement.*

*Participation in this study is voluntary and involves being interviewed for approximately 1 hour about your decision-making experience. The information you provide will be confidential. Those who participate in the study will receive a \$10 gift card.*

**If you are interested in participating in this study please call:**

**Laura A. Sardinia-Prager MSN, RN, CDDN, QDCP**

**(516) 849-8760**

**[lprager@molloy.edu](mailto:lprager@molloy.edu)**

**Appendix F: Field Memo Sheet****FIELD MEMO**

**ID of Contact:** \_\_\_\_\_  
**Telephone Number** \_\_\_\_\_  
**Interview Number:** \_\_\_\_\_  
**Date of Interview:** \_\_\_\_\_  
**Time of Interview:** \_\_\_\_\_  
**Site of Interview:** \_\_\_\_\_

1. **What were the main issues/themes that struck the researcher with this contact?**
  
2. **Summarize the information the researcher got (or failed to get) on each of the target questions for this contact:**
  - **Question number \_\_\_\_:**
  
  - **Information/Salient Points:**
  
  - **Themes/Codes:**
  
3. **Anything else that struck the researcher as salient, interesting, illuminating or important in this contact?**
  
4. **What new (or remaining) questions does the researcher have in considering the next telephone contact with this participant (or other participants) if indicated?**

**Appendix G: Confidentiality Statement for Transcriptionist****CONFIDENTIALITY Statement for Transcriptionist**

This statement will be signed by each transcriber prior to beginning transcription of digital audio interviews that will be transcribed verbatim into written transcripts.

I the undersigned understand that any information contained on the digital recorder, as well as that which I transcribe verbatim into a written document in reference to Parent's Decision Making about Residential Group Home Placement for their Adult Child with ID/DD belongs to the primary investigator of this research study, Laura A. Sardinia-Prager, MSN, RN, CDDN, QDCP. I will maintain privacy and confidentiality at all times during and after the process of transcribing these interviews.

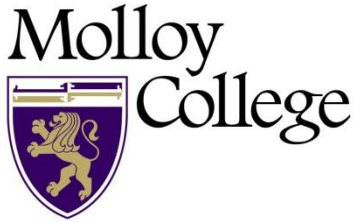
Signature of Transcriber: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix H: Telephone Screening Tool for Potential Participants**

### **Telephone Screening Tool for Potential Participants**

1. Telephone contact made to potential participant. Introduce myself, explaining I am a doctoral candidate at Molloy College PhD in Nursing completing my dissertation. Determine how they heard about my study.
2. Briefly explain the purpose of the study to explore how parents make the decision for residential group home placement for their adult child with ID/DD and the plan for the findings. Determine if they are the primary parent caregiver.
3. Discuss that the information will be obtained exploring a series of questions through a face-to-face digitally recorded interview process, as well as completion of a brief demographic questionnaire. All information will be kept confidential.
4. Discuss that the interview could last approximately 1 hour, with a follow-up telephone interview for further clarification from the original interview. Explain that a \$10 gift card honorarium will be given for their participation.
5. Explain to the potential participant inclusion and exclusion criteria for the study, as well as the consent process, and methods to maintain confidentiality.
6. Discuss that the interview would be conducted at a location and time convenient to the participant.
7. If the potential participant is interested in being part of the study provide them with; and obtain all necessary contact information for follow-up to arrange an interview time and location.

**Appendix I: Letter to Parents**

Division of PhD Nursing  
Molloy College  
1000 Hempstead Avenue  
Rockville Centre, NY 11571  
February 13, 2014

Dear Parent:

I am writing to ask you to participate in a doctoral study I am conducting as a Doctoral Candidate for a PhD in Nursing at Molloy College. The study will involve you participating in an interview lasting approximately one to one and a half hours. The interview will be conducted at a time and location of your convenience.

While the usual focus of the medical community, physicians, nurses, social workers, and mental health professionals is understandably on the child with an intellectual and developmental disability, little attention has been given as to how the disability affects parents when they need to make the decision regarding possible residential group home placement of their adult child with ID/DD.

I am exploring parent's decision-making experience regarding residential group home placement within the past 5 years of their adult child with ID/DD, and would like to hear from you. Participants can include parents who have decided for or against residential group home placement within the past 5 years.

Your participation in this study is voluntary. The information you provide will be confidential. Those who participate in the study will receive a \$10 gift card. I strongly believe that the results of this study will make a valuable contribution to better understanding and helping parents of all children with ID/DD in their decision-making experience regarding residential group home placement. I ask you to support my efforts by participating in this study.

If you are interested in participating in this study please call or e-mail:  
Laura A. Sardinia-Prager (516) 849-8760 or [lparger@molloy.edu](mailto:lparger@molloy.edu)

Thank you for your help.

Sincerely,

Laura A. Sardinia-Prager MSN, RN, CDDN, QDCP  
Doctoral Student (PhD Candidate)  
Molloy College  
Rockville Centre, NY  
[lparger@molloy.edu](mailto:lparger@molloy.edu)

## **Appendix J1: Concept Analysis**

### Background

A variety of other factors may result in the necessity for the parents to make the decision for residential group home placement of their adult child with ID/DD. Circumstances that may result in the need for a decision to be made could include aging parents, failing health of the parent caregivers, and financial or physical inability to provide care. After caring for the child with ID/DD for many years, the toll on the family dynamics and marital relationships, could possibly result in the need for the decision to be made for residential group home placement. Nurses are often part of the shared decision-making process when the family/caregiver of a person with ID/DD are making the decision for placement for their loved one from their family home into a residential group home setting.

Seeking greater conceptual clarity of the decision-making process would help to better explain what advocacy of shared decision-making means, the ability to recognize when it does occur, and may even help to encourage the practice of shared decision making by the interdisciplinary healthcare team, nurses, clinicians, patients, and families who have a preference for the joint shared decision making (Charles et al., 1997). Greater understanding and clarity of this phenomenon could inform creation of targeted interventions or strategies for this unique population by members of the interdisciplinary healthcare team. The creation of targeted interventions or strategies could potentially positively influence parent decision-making abilities and offer direction for further research.

### Observation

Preferences for both patients and physicians can differ tremendously and continuously change, thus the reason why inflexible characteristics for shared decision making cannot be developed because they would not fit this decision-making context. There is no one path to shared decision making and the characteristics outlined can be accomplished by a variety of actions (Charles et al., 1997).



## Appendix J2: Concept Analysis Definitions

The concept of Shared Decision Making process (SDM) will be defined by examining the critical attributes of the concept. *Merriam-Webster* (2013) defined the crucial elements as follows:

***Shared:*** to divide and distribute in shares; apportion; to partake of, use, experience, occupy, or enjoy with others; to have in common; to grant or give a share in; to tell; to have a share; to apportion; to talk about one's thoughts, feelings, or experiences with others.

Synonyms: participate, partake.

***Decision:*** the act or process of deciding; a determination arrived at after consideration; conclusion; a report of a conclusion; promptness and firmness in deciding; determination; win

Synonyms: award; call; conclusion; deliverance; determination; diagnosis, judgment; opinion; resolution; verdict.

***Making:*** the act or process of forming, causing, doing, or coming into being; a process or means of advancement or success; something made; potentiality; the material from which something is to be made.

Synonyms: material; raw material; stuff; substance; timber.

***Process:*** progress; advance; something going on; proceeding; a natural phenomenon marked by gradual changes that lead toward a particular result; a continuing natural or biological activity or function; a series of actions or operations conducing to an end;

Synonyms: course, operation, procedure; proceeding (*Merriam-Webster*, 2013).

### **Appendix J3: Concept Analysis Hypothetical Antecedents**

#### Antecedents

Rodgers (2000) described antecedents as situations or phenomena that precede the concept. Walker and Avant (2005) defined antecedents as critical elements that must occur prior to the concept. As previously stated, the focus of this concept analysis was shared decision making when the parents of a person with ID/DD are making the decision for placement for their adult child from their family home into a residential group home setting. Therefore, the need for shared decision making in this vulnerable population with ID/DD can become evident as a result of numerous factors including aging parents, failing health of the parent caregivers, financial or physical inability to provide care, and a variety of other circumstances. The toll on the family dynamics and marital relationships from the many years of caring for their loved one in the family home could possibly result in the need for the decision to be made for residential group home placement. Listed below are several possible antecedents.

- Inability for parent caregivers of the person with ID/DD to any longer provide care at home for their adult child with ID/DD.
- Increasing pressures on family life over an extended period of time with caring for the person with ID/DD.
- Change in the health status of the person with ID/DD requiring increased level of care that is greater than the parents are able to provide.

#### **Appendix J4: Concept Analysis Hypothetical Critical Attributes**

According to Rodgers (2000), analysis of the common use of a concept involves examination of its means of expressions or characteristics that help us clearly define a concept, decipher its strengths and limitations, and identify its functionality. A concept's attributes represent its real definition, making it possible to identify situations that fall under the concept, as well as those that can be characterized appropriately using the concept of interest (Rodgers, 1989). The critical attributes are a picture of the phenomenon of shared decision making focusing on the context of the unique vulnerable population of persons with ID/DD and their parents when the crucial decision for residential group home placement from the family home is appropriate to be made. The critical attributes are conditions and characteristics of the concept, and define only the particular concept. They include:

- An individual who is cognitively and developmentally impaired with limited understanding of choices or decisions necessary to be made for their future residential group home placement needs.
- Committed parent caregivers who would be faced with the necessity to make a decision regarding future residential group home placement needs of their adult child with ID/DD.
- Interdisciplinary healthcare team who would assist the parents in the shared decision-making process for the residential group home placement of the adult child with ID/DD.

## Appendix J5: Concept Analysis Hypothetical Consequences

Consequences of a concept refer to situations, events, or phenomena that follow an example of that concept and may include:

- Placement of the adult person with ID/DD in a residential group home.
- Feelings of guilt and failure may be experienced by the parent caregivers after placing the adult child with ID/DD in a residential group home.
- The parent caregivers may experience a sense of relief after placement of the adult child with ID/DD in a residential group home.
- Possibly improved family relationships/marriage after placement of the person with ID/DD in a residential group home.
- Increase in the health status may occur for the parent caregivers and/or the person with ID/DD after placement of the person with ID/DD in a residential group home from the family home.
- Possibility of the person with ID/DD remaining at the family home decreasing the financial burden on the healthcare system if residential group home placement does not occur; however, will result in an increase in at-home services cost (Rodgers, 2000).

Rodgers (2000) concluded that when an author provides a practical representation of a concept in a relevant context, this would be defined as an exemplar case. In concept analysis, a model case is an example of the concept that demonstrates all the defining attributes (Walker & Avant, 2005).

According to Walker and Avant (2005), in concept analysis, a contrary case is an example case that is a clear example of “not the concept.”

A borderline case in a concept analysis is constructed as another example of the concept's use. However, in the example of a borderline case, several of the defining attributes are purposefully excluded. Borderline cases allow readers to begin understanding what the concept is not (Walker & Avant, 2005).

## **Appendix J6: Concept Analysis Hypothetical Empirical Referents**

Empirical referents include measures of the defining attributes of the concept (Rodgers, 2000). The development and use of measurement tools to assess the outcomes of SDM interventions is important to advancing the area of decision making. Additional tools of measurement on parent's satisfaction with the Shared Decision-Making process would be appropriate as none of the studies in this literature review demonstrated using a measure for this context. Because of a growing desire for involvement in shared decision making, and the increased number of studies in the area, it would be important for improvement of the data collection tools in this type of research (Mullen et al., 2006). There are currently several tools available; however, they measure patient satisfaction with treatment decisions and include: Decisional Conflict Scale, Satisfaction with Decision Scale, Decisional Self-Efficacy Scale, and Satisfaction With the Decision-Making Process.

O'Connor's Decisional Conflict Scale (Katapodi, Munro, Pierce, & Williams, 2011; O'Connor, 1995, 1998) has 16 Likert-type items and three subscales: Uncertainty, Effective Decision-Making, and Factors Contributing to Uncertainty.

Satisfaction with the Decision Scale is a tool developed to measure satisfaction with treatment decisions with 6 items that assess adequacy of information, consistency of the decision with personal values, belief in ability to carry out the decision, opportunities for sufficient input into the decision and whether the overall decision was satisfactory, and satisfaction with the decision-making process (Wills & Holmes-Rovner, 2003).

The Decision Self-Efficacy Scale measures self-confidence or belief in one's abilities in decision-making, including shared decision-making (O'Connor, 2002).

## **Appendix J7: Concept Analysis Hypothetical Model Case**

### **Hypothetical Model Case**

Patrick, 49 years of age, was the oldest of four children of a middle-class family. He was born with Down syndrome, moderate Intellectual/Developmental disability, congenital heart abnormalities, epilepsy, Obsessive Compulsive disorder, and limited cognitive understanding with the inability to make decisions for himself. Patrick's father was a New York City Police Officer and his mother a homemaker. Patrick's mother, Ann, devoted the majority of her life committed to caring for him in their modest home in the suburbs. Patrick attended a Day Program sponsored by a local agency where he was able to interact with a group of his peers. Over the past few years, Patrick has become increasingly dependent on his mother for his medical care and activities of daily living as he is now, in addition to all of his other medical concerns, displaying early signs of Alzheimer's disease. Concurrently, Ann has unfortunately developed her own health problems and had recently undergone cardiac bypass surgery, making it more and more difficult for her to meet Patrick's increasing needs. During the past few years members of the interdisciplinary team (nurses, physicians, social workers, service coordinators, and the program coordinators) at Patrick's Day Program have been discussing and planning with Ann and her husband future options for Patrick's care. Information for the various options available has been provided to the caregivers both verbally and with written material. At each subsequent meeting, the parents were encourage to ask questions or seek clarification regarding any of the information they received. A few years ago, after extensive discussion with the parents informing them of various options, the interdisciplinary team, nurses, clinicians, and the parents decided that future group home placement would be appropriate for Patrick. The interdisciplinary team, nurses, and clinicians assisted the parents in placing Patrick on a waiting

list for residential group home placement. The interdisciplinary team, nurses, and clinicians professional experience gave the parents the knowledge that it can take several years before availability of an opening in a home for placement can occur. Fortunately, the early planning and shared decision-making that occurred between the interdisciplinary team, nurses, clinicians, and the parents allowed for a smooth transition from the family home to the residential group home setting. Patrick has recently been placed in a residential group home setting with his peers where he receives 24 hour nursing support. Both Patrick and his parents had a smooth transition to his new living arrangements. This case contains all the critical attributes of an individual that is cognitively and developmentally impaired with limited understanding of choices or decisions necessary to be made for their future residential group home placement needs. The case also includes committed parent caregivers who would be faced with the necessity to make a decision regarding future residential group home placement needs of their family member with ID/DD; and an interdisciplinary healthcare team, nurses, and clinicians that would assist the parents in the shared decision-making process for the residential group home placement of the adult child with ID/DD.

## **Appendix J8: Concept Analysis Hypothetical Contrary Case**

### **Hypothetical Contrary Case:**

Cathy is a high-functioning 33-year-old individual with mild ID/DD who lives independently in an apartment. She travels to her work at a community workshop daily via mass transportation. Although Cathy has multiple medical conditions including hypertension, diabetes, osteoarthritis, anxiety disorder, obsessive compulsive disorder and gastro-esophageal reflux disease she remains independent with her activities of daily living, finances, medical care, and is capable of making decisions for herself. She visits her family on a weekly basis for Sunday dinners. Cathy has a boyfriend, Robert, whom she works with at the community workshop. Cathy and Robert plan to get married in the near future and buy a home in the suburbs. Cathy's case is considered a contrary example because none of the critical attributes were present. Although Cathy had mild ID/DD she was not cognitively or developmentally impaired to the extent where she would have limited understanding of choices or decisions that needed to be made. The attribute of committed parent caregivers was not indicated in this case because Cathy is independent with her care. There was no need for intervention of the interdisciplinary healthcare team, nurses, or clinicians to assist the family in a shared decision-making because Cathy was independent and planning to get married and purchase her own home with her new husband.



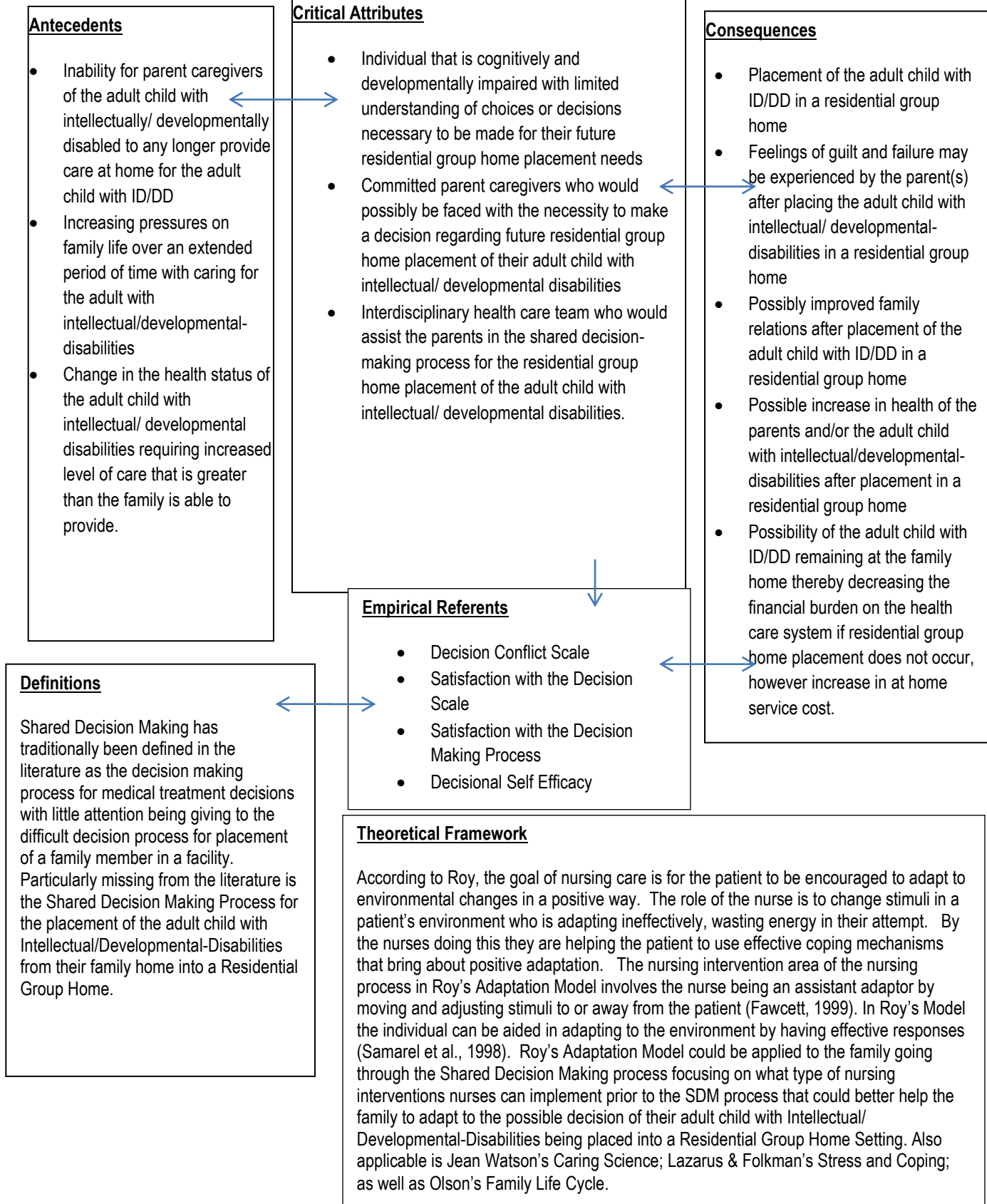
## **Appendix J9: Concept Analysis Hypothetical Related/Borderline Case**

### **Hypothetical Related/Borderline Case:**

Theodore is a 60-year-old ID/DD man with severe ID/DD who is cognitively and developmentally impaired. He is an only child and has lived at home with his extremely wealthy parents his entire life. His father, who was always the sole caregiver of Theodore has recently passed away and his elderly mother is not committed to personally providing any of the necessary care that her son requires. However, Theodore's mother is financially secure and has privately arranged for twenty-four hour staff in the home to meet all of Theodore's needs.

This is an example of a related/borderline case because some of the attributes were purposely omitted. Although the critical attribute included was that of Theodore as a profoundly ID/DD individual who is cognitively and developmentally impaired, with limited understanding of choices or decisions necessary to be made; this was the only attribute included in the case. Since the death of his father, he no longer has a committed parent who is willing to personally care for him and meet his healthcare needs. His mother was not previously involved in his care and has no desire to do so, even after the death of Theodore's father. Because of the mother's significant financial status, she has independently made the decision to arrange to hire others for complete care of her adult son, in the home. The decision occurred without any shared decision making with the interdisciplinary team, nurses, or clinicians; nor was there at any time, any consideration for residential group home placement.

## Appendix J10: Suggested Concept Analysis Map



### Appendix K: Demographics of Participants

ID#	#1	#2	#3	#4	#5	#6a	#6b	#7	#8	#9	#10	#11	#12	#13	#14	
Age	56	62	52	66	71	65	71	62	57	70	56	63	59	54	67	
Gender	F	M	F	F	F	F	M	F	F	F	F	F	F	F	F	
Racial/ Ethnic	W	W	W	W	W	W	W	W	W	W	W	Hisp	W	W	W	
Marital Status at Decision	M	M	M	M	M	M	M	M	M	M	Sep	M	M	M	Wid	
Marital Status now	M	M	M	M	M	M	M	M	M	M	Part	M	M	M	Wid	
# of children in the family	4	2	4	3	2	2	2	2	2	7	3	3	2	6	5	
# of children living in home at decision	4	2	4	1	2	2	2	1	1	3	3	3	2	2	N/A	
Parent educa- tion level	Bach	Bach	HS	Bach	Bach	Mast	Mast	Bach	AD	HS	HS	Bach	Mast	AD	AD	
# of years cared for child at home	26	21	22	23	37	20	20	23	22	19.5	23	25	22	26	42	
Work outside home	Yes	Yes	No	No	No	No	No	No	No	No	Yes	No	Yes	Yes	Yes	
Year of place- ment	2011	2008	2010	2011	2010	2010	2010	2013	2013	2008	2008	2007	2009	2014	N/A	
# of years on waitlist	8	5	9	5	22	14	14	6	10	3mon	2	4	7	8	N/A	
Birth order of child	3 of 4	Oldest	Oldest twin	Young	Oldest	Oldest	Oldest	2 <sup>nd</sup> adopted	Young	Young	Oldest	Mid	Oldest	Young	Oldest	
Age of child at place- ment	26	21	22	23	37	20	20	23	22	20	23	25	22	26	N/A	
Born or acquired diag- nosis	Born	Born	Born	Born	Born	Born	Born	Born	Born	Born	Born	Born	Born	Acquir ed	Traum a at birth	Born

**Legend:**

**Gender:** M=Male, F=Female

**Racial/Ethnic:** W=White, Hisp=Hispanic

**Marital Status:** M=Married, Sep=Separated, Part=Partner, Wid=Widow

**Parent Education Level:** AD=Associate Degree, Bach=Bachelor Degree, Mast=Masters or above

**N/A**=Not applicable as the adult child has not be placed into a residential group home

### Appendix L: Primary Diagnosis of the Adult Child Placed in Residential Group Home

<b>Parent Interviewee</b>	<b>Child of Interviewees</b>	<b>Organization Where the Individual with ID/DD Resides</b>	<b>Diagnosis</b>
<b>Interview #1</b> Patricia	<b>Interview #1</b> Carla	Association for the Help of Retarded Children (AHRC)	Down Syndrome
<b>Interview #2</b> Javon	<b>Interview #2</b> Edward	Family Residences and Essential Enterprises, Inc. (FREE)	Autism Spectrum Disorder
<b>Interview #3</b> Catherine	<b>Interview #3</b> Samantha	Mary Haven	Cerebral Palsy
<b>Interview #4</b> Illyse	<b>Interview #4</b> Peter	Family Residences and Essential Enterprises, Inc. (FREE)	Autism Spectrum Disorder
<b>Interview #5</b> Emilia	<b>Interview #5</b> Carmine	Life's WORC	Down Syndrome
<b>Interview #6</b> Betty 6A Raphael 6B	<b>Interview #6</b> Laura	Life's WORC	Smith-Magenis Syndrome
<b>Interview #7</b> Jennifer	<b>Interview #7</b> Theodore	Community Mainstreaming Associates, Inc. (CMA)	Asperger's Syndrome
<b>Interview #8</b> Rita	<b>Interview #8</b> Racquel Michael	Community Mainstreaming Associates, Inc. (CMA)	Smith-Lemli-Opitz Syndrome
<b>Interview #9</b> MaryAnn	<b>Interview #9</b> Marissa	Life's WORC	Rett Syndrome
<b>Interview #10</b> Karen	<b>Interview #10</b> Kristen	Family Residences and Essential Enterprises, Inc. (FREE)	Prader-Willi Syndrome
<b>Interview #11</b> Edie	<b>Interview #11</b> Robert	Family Residences and Essential Enterprises, Inc. (FREE)	Agenesis of the Corpus Callosum Autism
<b>Interview #12</b> Debra	<b>Interview #12</b> Stanley	Association for the Help of Retarded Children (AHRC)	Autism Spectrum Disorder
<b>Interview #13</b> Talia	<b>Interview #13</b> Angela	Family Residences and Essential Enterprises, Inc. (FREE)	Prader-Willi Syndrome
<b>Interview #14</b> Valerie	<b>Interview #14</b> Joey	Lives at home with parent	Moderate ID/DD

### Appendix M: Measures of Trustworthiness in Qualitative Research

Qualitative Paradigm Criteria	Key Concept	Techniques Used in This Study
Credibility	Truth value	Prolonged engagement 2 ½-4 hours over 15 months, member checks; expert debriefing; telephone interview; triangulation-interview transcripts, field notes, operational and theoretical memos, contact summary sheet; persistent observation; rich excerpts from transcripts; negative case analysis.
Transferability	Applicability	Maximum variation sampling; theoretical sampling; thick description of the data; summary of the sample demographic characteristics.
Dependability	Consistency	Audit trail of operational and theoretical memos; audit trail outlined all decisions made by the investigator at every stage of the data analysis; field notes; 2 digital recorders; NVivo aggregated collection of phrases were reviewed by committee members. Dissertation committee was consulted regularly during the theoretical coding process.
Confirmability	Neutrality	The investigator was aware of the researchers contribution to the construction of meanings throughout the research process therefore personal reflexivity; member checks; reflexive journal; confirmability audit were utilized.

### Appendix N: Watson's Caritas Processes

Carative Factors	Caritas Processes
1. "The formation of a humanistic-altruistic system of values"	"Practice of loving-kindness and equanimity within the context of caring consciousness"
2. "The instillation of faith-hope"	"Being authentically present and enabling and sustaining the deep belief system and subjective life-world of self and one being cared for"
3. "The cultivation of sensitivity to one's self and to others"	"Cultivation of one's own spiritual practices and transpersonal self going beyond the ego self"
4. "Development of a helping-trust relationship"	"Developing and sustaining a helping, trusting authentic caring relationship"
5. "The promotion and acceptance of the expression of positive and negative feelings"	"Being present to, and supportive of, the expression of positive and negative feelings as connection with deeper spirit and self and the one-being-cared for"
6. "The systematic use of the scientific problem solving method for decision making" became "Systematic use of a creative problem solving caring process"	"Creative use of self and all ways of knowing as part of the caring process; to engage in the artistry of caring-healing practices"
7. "The promotion of transpersonal teaching-learning"	"Engaging in genuine teaching-learning experience that attends to unity of being and meaning, attempting to stay within others' frame of reference";
8. "The provision of supportive, protective, and (or) corrective mental, physical, societal, and spiritual environment"	"Creating healing environment at all levels (physical as well as nonphysical, subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated)"
9. "The assistance with gratification of human needs"	"Assisting with basic needs, with an intentional caring consciousness, administering 'Human care essential,' which potentiate alignment of mind, body, spirit, wholeness, and unity of being in all aspects of care"
10. "The allowance for existential-phenomenological forces" became allowance for existential-phenomenological-spiritual forces"	"Opening and attending to spiritual-mysterious and existential dimensions of one's own life-death; soul care for self and the one-being-cared for"

## Appendix O: Letter of Approval from Molloy College IRB



1000 Hempstead Avenue  
Rockville Centre, NY 11571  
[www.molloy.edu](http://www.molloy.edu)

Tel. 516.323.3653  
Tel. 516.323.3801

Date: January 7, 2014  
To: Laura Sardinia Prager  
From: Kathleen Maurer Smith, PhD  
Co-Chair, Molloy College Institutional Review Board  
Veronica D. Feeg, PhD, RN, FAAN  
Co-Chair, Molloy College Institutional Review Board

**SUBJECT: MOLLOY IRB REVIEW AND DETERMINATION OF EXPEDITED STATUS**  
**Study Title:** A Grounded Theory Study of How Parents Made the Decision About Residential Group Home Placement for their Adult Child With Intellectual/Developmental Disabilities (ID/DD)  
**Approved:** **January 7, 2014**

Dear Laura:

The Institutional Review Board (IRB) of Molloy College has reviewed the above-mentioned research proposal and determined that this proposal is approved by the committee. It is considered an EXPEDITED review per the requirements of Department of Health and Human Services (DHHS) regulations for the protection of human subjects as defined in 45CFR46.101(b) and has met the conditions for conducting the research.

You may proceed with your research. Please submit a report to the committee at the conclusion of your project.

Changes to the Research: It is the responsibility of the Principal Investigator to inform the Molloy College IRB of any changes to this research. A change in the research may change the project from EXPEDITED status that would require communication with the IRB.

Sincerely,

Kathleen Maurer Smith, PhD

Veronica D. Feeg, PhD, RN, FAAN