PLAINTIFFS'
EXHIBIT

PPI 0777

IN THE UNITED STATES DISTRICT COURT
FOR THE WESTERN DISTRICT OF TEXAS
SAN ANTONIO DIVISION

ERIC STEWARD, by his next friend	§	
and mother, Lilian Minor, *et al.*,	§	
	§	
Plaintiffs,	§	
	§	
v.	§	
	§	
	§	
CHARLES SMITH, Governor, *et al.*,	§	
	§	
Defendants.	§	
______________________________	§	CIV. NO. 5:10-CV-1025-OG
	§	
THE UNITED STATES OF AMERICA,	§	
	§	
Plaintiff-Intervenor,	§	
	§	
v.	§	
	§	
THE STATE OF TEXAS,	§	
	§	
Defendants.	§	

PLAINTIFFS' AND UNITED STATES' DECLARATION AND EXPERT DISCLOSURE FOR LAUREN CHARLOT, Ph.D.

I declare under the pains and penalties of perjury under the laws of the United States and in compliance with Fed. R. Civ. P. 26(a)(2)(B) that the foregoing is true and correct and that I am submitting this disclosure regarding my work as an expert consultant in the above case:

1. I have been retained by the Plaintiffs and the United States as a joint expert in the *Steward v. Smith* litigation.

2. My report, which is attached, contains a complete statement of all of my opinions as well as an explanation of the basis and reasons for those opinions.

3. My report describes the facts, data and other information I considered in forming my opinions.

4. There are no exhibits prepared at this time to be used as a summary of or support for my opinions.

5. My attached curriculum vitae states my qualifications and lists all publications I have authored within the past ten (10) years.

6. Within the last four (4) years, I have not testified as an expert, either in a deposition or at trial.

7. My compensation in this litigation is $1200.00/day or $150.00 per hour for preparation of reports and statements, and for deposition or testimony, plus expenses. My compensation is not dependent on the outcome of this litigation.

This information is accurate and complete to the best of my knowledge, information and belief.

Signed and dated:

3-30-18

Lauren Charlot, Ph.D.

CERTIFICATE OF SERVICE

I certify that on this 30th day of March, 2018, a true and correct copy of the foregoing Plaintiffs' and the United States' Declaration and Expert Disclosure for Lauren Charlot, Ph.D. was delivered via electronic mail and Federal Express to the attorneys for defendants at the addresses below:

Elizabeth Brown Fore
Elizabeth.BrownFore@oag.texas.gov
Thomas A. Albright
Thomas.Albright@oag.texas.gov
Drew Harris
Drew.Harris@oag.texas.gov
Andrew B. Stephens
Andrew.Stephens@oag.texas.gov
Christopher D. Hilton
Christopher.Hilton@oag.gov
Natalee B. Marion
Natalee.Marion@oag.texas.gov
Rola Daaboul
Rola.Daaboul@oag.texas.gov
Jeffrey Farrell
Jeffrey.Farrell@oag.texas.gov
Attorneys General
General Litigation Division
P.O. Box 12548, Capitol Station
Austin, Texas 78711-2548

Counsel for Defendants

/s/ Garth A. Corbett
GARTH A. CORBETT

IN THE UNITED STATES DISTRICT COURT
FOR THE WESTERN DISTRICT OF TEXAS
SAN ANTONIO DIVISION

ERIC STEWARD, by his next friend	§	
and mother, Lilian Minor, *et al.*,	§	
	§	
Plaintiffs,	§	
	§	
v.	§	
	§	
	§	
CHARLES SMITH, Governor, *et al.*,	§	
	§	
Defendants.	§	
____	§	CIV. NO. 5:10-CV-1025-OG
	§	
THE UNITED STATES OF AMERICA,	§	
	§	
Plaintiff-Intervenor,	§	
	§	
v.	§	
	§	
THE STATE OF TEXAS,	§	
	§	
Defendants.	§	

EXPERT REPORT OF LAURIE CHARLOT, Ph.D.

I. Purpose and Scope

This report contains my findings from my review of a sub-sample of individuals with intellectual and developmental disabilities (IDD) living in nursing facilities in Texas.

The purpose of this review was to evaluate: the execution of the Pre-admission Screening and Resident Review (PASRR) process and the provision of specialized services and active treatment; the service and transition planning process; whether the person would benefit from community living; and whether the person got enough information about community living to make an informed choice, and if they did make an informed choice, to remain in the nursing facility.

II. Experience

I am a Developmental Psychologist, with a clinical license in social work, a bachelor degree of science in psychology, a master's degree in clinical social work and a doctorate in developmental and educational psychology. I have been working with individuals with IDD for over 30 years.

I am currently working as an independent consultant. I am a consultant to the National Center for START Services, a program of the University of New Hampshire Institute on Disabilities, where I provide program consultation and training on request. The focus of my work in this program is in providing special trainings and teaching clinicians how to perform assessments. I have been an assistant professor of psychiatry at the University of Massachusetts Medical School and am an adjunct professor at East Carolina University in their respective Medical School/Departments of Psychiatry and have provided training regarding IDD to physicians in training at these schools. As the Director of the Becket Multidisciplinary Consultation Team for Individuals with ID and Mental Health Disorders, I continue to run quarterly clinics with a multidisciplinary team evaluating people with IDD who have complex needs and for whom there has been diagnostic confusion. In many of these cases, a key factor contributing to the person's poor mental health is the lack of a good fit in terms of their living environment. Usually, the problem centers on individuals not being meaningfully engaged in their communities, and lacking a normal community-based social network. The latter has been repeatedly found to be one of the most important protective factors that will help people at risk to stay mentally well (and not develop a psychiatric disorder).

I have published original research, and lectured widely on a variety of topics related to the care of individuals with IDD and Autism Spectrum Disorders (ASDs) across the United States, Canada and in Europe. I was a Co-Principal Investigator with the Director of the E.K. Shriver Center on a National Institutes of Health-funded grant studying depression in children with ID and was the Principal Investigator for a University of Massachusetts Medical School Internal Initiatives Grant in which we studied the occurrence of medical problems in patients with IDD. In this project, several of the participants enrolled in our program were residents of a facility that was closing. Their families for the most part objected to moving them into community care. However, these individuals had very successful moves to the community and were able to be part of their communities again. One group I visited several times moved into a home in the suburbs with a beautiful back yard with flowers and trees, and floor to ceiling windows. They were able to do things such as going to activities in the community that they would not have attended or would have attended much less often when in the facility. They were able to be treated with much less psychoactive medication, which formerly was thought to be necessary to manage their challenging behaviors and emotional distress when they were institutionalized. In many cases, this was associated with improved physical health as well. This experience reinforced for me how much is possible for people with even very significant clinical needs, and highlighted the extent to which living in one's community contributes to improved physical and mental health when individualized services are provided.

I was the lead author on the National Association for the Dually Diagnosed (NADD) sponsored Diagnostic Manual for People with ID (DM-ID) 2 chapter on Depressive Disorders, and have also contributed to other chapters.

I have designed and directed multiple acute inpatient and outpatient psychiatric services for individuals with IDD and ASD, providing oversight in program development, operations and training to personnel within these varied programs. I continue to conduct multidisciplinary evaluations of people with IDD with a team of physicians. In many of these assessments, we find that people who are not able to be engaged in their community and who do not have active treatment (having opportunities to be needed, busy and engaged in things they enjoy and care about doing) seem to suffer emotionally from this.

I have acted as a federal court monitor in two settlement agreements addressing the needs of people with IDD. These cases include *Marr v. Eastern State Hospital, et al.*, No. CV-02-0067-WFN (E.D. Wash.), in which I was a mutually agreed upon, Court-appointed settlement monitor and *Jimmie, et al. v. Dep't* of

Pub. Welfare, Civ. Action 3:09-cv-1112-ccc (M.D. Pa.) in which I served as a consultant reviewing the implementation of a settlement agreement. Earlier in my career, I conducted evaluations of individuals with IDD to determine if they could make important informed choices or if they needed assistance for things like determining where they should live, or making choices about medical interventions. Assessing the basic mental status of people with IDD is part of the assessments I conduct on a routine basis in my clinics.

Over the course of these and other experiences throughout my career, I have been able to see a large number of individuals with IDD, many of whom have significant challenges to their health and/or their behavior, who resided in a wide variety of living situations. I have observed how systems of care are able to develop plans, and deliver individualized, person-centered care for most all people in their communities. I learned the core values of the service system that supports individuals with IDD, especially those persons who have very complex service needs due to medical and behavioral health challenges. These core values include an extreme commitment to providing care to people with IDD in their communities, and a focus on promoting and supporting individuals' attaining and maintaining independence and self-determination to the greatest extent possible. I have learned about the history of care of people with IDD that propelled key changes in how care is delivered, including the establishment of regulatory guidelines such as PASRR, that help ensure people with IDD are not segregated, and that they have access to appropriate services provided in the least restrictive settings possible.

My curriculum vitae is attached as Attachment A.

III. Materials Reviewed

In conducting my review, I reviewed approximately two years of nursing facility and Local Intellectual and Developmental Disability Authority (LIDDA) records, as were requested by attorneys for Plaintiffs and the United States from nursing facilities and LIDDAs. These records were made available to me through a secure online database. I reviewed available records prior to my interviews and also reviewed additional records received after the interviews. When possible, I also reviewed certain records onsite at the nursing facility.

In addition, I reviewed background documents including federal and Texas PASRR and related regulations, and Texas policies and procedures governing PASRR processes and the services available to people with IDD.

A complete list of all documents I considered is attached as Attachment B.

IV. Methodology

I understand that a sample of people were randomly selected meeting the criteria of having IDD and being persons who currently reside in a nursing facility in Texas, and were therefore eligible for PASRR services. I understand the sample was limited to certain geographical areas. I reviewed a subset of these people. The subset of people for whom I conducted a review consisted of 14 individuals, including a group who lived in and around the Dallas area, and a group who lived in southern Texas in the San Antonio and Corpus Christi areas.

There are three other experts, Barbara Pilarcik, RN, Dr. Vickey Coleman, and Natalie Russo, RN, who also conducted reviews of individuals in the sample. Ms. Pilarcik conducted trainings with us to ensure we conducted our reviews consistently. Ms. Pilarcik also instructed all of us to use a guiding document that included the findings we were to make and the factors we were to consider in reaching those findings. I reviewed this document in advance, discussed with the other three reviewers, and provided comments on the factors we would consider.

I was asked to review 18 individuals in the sample. Initial plans had to be modified due to the two successive hurricanes. Hurricane Harvey caused extensive flooding in areas I planned to visit and, even after delaying my travel to the gulf coast area for a week, I was unable to see one individual in this area. I was also unable to finish my last day of interviews, of two individuals, because of an emergency situation requiring I return to secure my home, which was located in an area within which a mandatory evacuation warning was issued due to Hurricane Irma. Ultimately, I met and interviewed 15 individuals. One of these individuals was a woman who was not PASRR positive because she did not have an intellectual or developmental disability, and therefore I did not further pursue a review of her case.

Over the course of my interviews with the individuals in my sample, I explored the nature of the care being provided and asked about PASRR assessments and services. In each case, I sought to understand some background and personal characteristics of the person (i.e., how does this individual communicate, what were the things most important to this person, their preferences and interests, their experiences in the nursing facility, history, etc.), to the extent possible in the time available. With the individuals from the sample, and guardians or Legally Authorized Representatives (LARs) where appropriate, I also asked questions to elucidate to what extent these individuals understood basic facts about the IDD system of care and various options for services. In some instances, I asked questions aimed at assessing if the individual with IDD appeared to have basic reasoning skills and if they seemed to understand simple verbal constructions. I was not conducting an in-depth clinical assessment, but speaking with people and looking at materials as a way of understanding the basics of how the PASRR process was implemented with these individuals and as much as possible, what they understood it meant for them individually.

To conduct my review, I spent about three hours conducting each interview and site visit. I interviewed the individual identified; nursing facility staff, including nursing staff familiar with the person, administrators, rehabilitation therapy staff and social workers, as available; and LIDDA service coordinators and/or service coordinator supervisors. I met with family members, LARs, or guardians, when appropriate. I reviewed the nursing facility and LIDDA records available to me and also looked at certain records during the visits if these were available and time permitted when interviews were completed. The process described above is consistent with my professional standards for assessing individuals with IDD.

Through this process, I sought to examine individually if the person was provided with comprehensive functional assessments, specialized services and active treatment, and opportunities for community living as outlined in regulations that govern PASRR implementation in Texas and professional standards for serving individuals with IDD. I also sought to determine if there were any clear patterns of problems in understanding the barriers to implementing the PASRR processes for the individuals I reviewed.

V. Standards

Following are the standards that I applied in reaching my conclusions in this review.

A. PASRR Specialized Services and Active Treatment

In order to ensure individuals with IDD receive needed services and supports, proper screening, identification, and assessment is important. Federal and Texas rules require that any person entering a nursing facility receive a PASRR Level I screening, which is supposed to identify if the person might have ID or DD. If the PASRR Level I does identify a suspected IDD, it should trigger a Level II PASRR Evaluation.

This PASRR Evaluation should determine whether the person has IDD, and if so, determine whether the person's needs could be met in the community and identify the specialized services they need if they are admitted to the nursing facility. The needed specialized services are supposed to be determined based on an assessment of fifteen habilitation areas of need for the individual.

Individuals with IDD should receive a comprehensive functional assessment of all habilitative areas that accurately identifies all of that person's strengths and needs. Comprehensive functional assessments must be done because they form the foundation for all further work such as developing an Individual Service Plan (ISP) and identifying service needs and the plans required to meet these needs. A comprehensive functional assessment should include a broad range of areas, including physical development and health; medications; self-monitoring of health; self-monitoring and scheduling of medical treatments; nutritional status; self-help development; sensorimotor development; affective development; speech and language development; auditory functioning; cognitive development; social development; adaptive behaviors, independent living skills and skills needed for community living; as well as vocational skills. These assessments must be timely, conducted within a short time of each other, and there must be a timely reassessment when needs and conditions change to insure that the plans are relevant to the person's current needs. Assessments should also be performed by a professional with qualification and training in serving individuals with IDD.

Assessments must also be comprehensive in nature (not cursory or failing to be specific to the individual, as when assessments are entirely constructed of check boxes, without any personal details). To be comprehensive, these assessments must cover all of the areas in the person's life where provision of services and plans can be developed that will help the person have as much autonomy and function as independently as possible, while meeting safety, medical and other basic needs. Comprehensive assessments, and the plans derived from them, must help support people with IDD to live in the least restrictive setting possible and where possible, the aim is always for the person to be able to have a life in their community.

Federal and Texas law require the provision of specialized services to individuals with IDD who reside in nursing facilities. Specialized services are habilitative services that are aimed at preserving function, preventing regressions and teaching skills that help the person be as independent as possible and be prepared to live in their community if possible (in the least restrictive setting that can meet their needs). Texas provides some specialized services through the nursing facility and some specialized services through the LIDDA. Nursing facility specialized services are habilitative therapies, such as physical therapy (PT), occupational therapy (OT), speech therapy (ST); customized manual wheelchairs (CMWCs); and durable medical equipment (DME). LIDDA specialized services are service coordination, independent living skills training (ILST), day habilitation, supported employment, employment assistance, and behavioral support.

Specialized services must be provided with the appropriate intensity, frequency and duration to achieve these goals for the individual. Needed specialized services should be incorporated into ISPs and Nursing Facility Care Plans (NFCPC) in order to ensure coordination, and the service coordinator should monitor provision of the specialized services.

Specialized services, together with usual nursing services, should constitute a program of active treatment for the individual. Continuous active treatment programs are required in institutional settings that serve individuals with IDD, and should include aggressive implementation of a program of specialized and generic training, treatment, health services and related services. Continuous active treatment programs must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible. Additionally, a continuous active treatment program should be designed to maintain skills and functioning and prevent further regression to the extent possible; and these treatments must be provided in settings, such as the community, that facilitate acquisition of skills enabling the individual to function with as much self-determination and independence as possible. Continuous active treatment must be delivered consistently across settings at all times, relevant to the acquisition of skills and the opportunities to practice those skills. Active treatment requires that the person has a daily set of activities that have been developed to help meet both habilitative and rehabilitative needs. There seemed to often be confusion among the nursing facility and some LIDDA staff regarding habilitative services versus rehabilitative services with many believing that payment for services such as PT, OT and ST are only possible when a person shows decline and ongoing, only if the person is making progress. Somehow, the need to prevent loss of skills for many people with IDD that is a habilitative service was underappreciated. Active treatment needs to happen across days and time of day and on weekends, and across settings and situations. This is needed for most people with IDD to generalize skills and to consolidate learning.

A professionally-appropriate approach to planning and coordinating the delivery of services and achieving goals for individuals with IDD is the use of an ISP that is developed based on comprehensive, person-centered assessment including all needed services and supports to successfully transition to the community. An ISP must be based on a comprehensive assessment of the individual's interests, strengths, needs, preferences, concerns, and barriers regarding community living and these must be documented. It is necessary for the ISP to clearly incorporate the results of the comprehensive functional assessment, and to include goals for transition, a plan to enable the individual to make an informed choice about community living, and strategies to address any barriers to community living. Obstacles to transition to the community should be explored and documented and the benefits to the individual of living in the community should be fully considered and explored by the team. It is important that what a person needs for community living is not considered only based on what currently exists in a given community, but what the person actually needs. The ISP must be implemented fully and implementation of the ISP must be consistent with the needs and preferences of the individual. In many of the ISPs, documentation was staff-centric and not person-centered. In one case, for example, it was suggested that what people liked most about the individual with IDD was that he was content living at the NF. In many cases the individual was asking for more opportunities to be out in his community but the ISP would include few references to this, such as KD. Being person-centered is a critical value and a regulatory requirement in the ISP process. This is where all of us who provide care to people with disabilities try to place ourselves in the person's shoes and do our best to capture what is really important to that person in those instances where he or she cannot articulate this clearly on their own.

B. Benefits from Community Living

It is widely accepted that individuals with IDD benefit from living in the most integrated setting with appropriate community services and supports. For this reason, it is critical that the default position is never to just stay in a facility and to not live in one's community because of a lack of effort to explore possible options.

The research is overwhelming in support of the finding that people with IDD fare much better when living in the community as compared with facility-based care. This is especially true in terms of developing skills that allow for greater autonomy. It is well documented that having a life in one's community is far better than residing in segregated settings (Kim, Larson & Lakin, 2001; Kozma, Mansell & Beadle-Brown, 2009). In fact, it is understood that systems of care should be organized to ensure that everything possible is done to provide people with disabilities a life in their community, and to support their growth in and maintenance of skills that will permit community living.

Many studies have demonstrated that people with IDD who live and work in community settings have more opportunities to make choices, and that this helps them be able to exercise their right to self-determination. Experts have found that when individuals with significant disabilities are provided choices, they have greater independent living outcomes and increased quality of life outcomes. It is an established, research-based finding that people with IDD who live in segregated facility settings have fewer opportunities to make choices and, therefore, reduced abilities to develop and maximize independence (Joannou & Wolf, 2011). These findings have all contributed to a commitment to help people live and receive services in the least restrictive care settings possible.

C. Informed and Meaningful Choice

In the provision of services to individuals with IDD, it is important to ensure that the individual or their guardian makes an informed choice about what services to receive. This is especially true with respect to the decision to remain in a segregated nursing facility. In order to ensure that an individual is able to make an informed choice, individualized information must be provided to the individual and, if applicable, guardian, regarding community living, which in Texas should be provided through the Community Living Options (CLO) counseling process. Further, individualized opportunities must be provided to the individual to experience community living and to promote understanding of what this might be like. Specialized services provided to the individual can be one opportunity to enable the person to experience and develop skills for community living, but they must be designed to do so, and individualized information should be provided to the person or guardian, regarding how his/her needs would be met in an integrated setting. This information should be provided regularly and in multiple formats. It is important that the person presenting options to the individual has used every possible tool to address barriers and to insure the person really understands options so the default position is not simply to stay in a facility. In order to inform the provision of individualized information it is important to document the circumstances leading to admission; the individual's interests, needs, strengths, preferences, concerns, and barriers regarding community living; and the steps taken to address these.

Some people with IDD have difficulty understanding their options and making choices and need significant help to ensure they understand options. In some cases, family or even professional guardians are needed, although often simply the right kind of supports will be sufficient. It is important for service providers and advocates, when trying to ascertain what are the real wishes of a person with IDD, when individuals have difficulties with expressive language or have cognitive disabilities that that they are provided with all needed information and adequate supports to express their desires. For example, in one person's case in my sample (MM's), family members had asked for habilitative speech therapy (the request was not honored), because their loved one often fails to tell others when she is ill, and she typically will not assert herself regarding her wishes and needs.

Professionals need to use their understanding of each unique individual's profile of cognitive and other strengths and weaknesses, to ensure that, as much as possible, the plans and treatments provided are those that this person would want, as well as what is needed for optimal outcomes (i.e., social awareness, sensorimotor, communication, behavioral, information processing, daily living and other adaptive skills, community living skills). In all areas, it is a goal of professionals tasked with supporting people with IDD to provide person-centered care, sensitive to people's real preferences. When individuals end up living in institutional settings like nursing facilities, they often have to sacrifice many daily choices and control over their daily lives.

There are several factors that contribute to the challenge of ensuring the wishes of people with IDD are recognized, appreciated and acted upon. One of the well-known psychological consequences of living in facility based care, like a nursing facility, is a phenomenon known as *Learned Helplessness. Learned Helplessness* is "a condition in which, over time, a person feels helpless to control or change conditions affecting them, leading to the person behaving as if he or she is in fact helpless, without even trying to make changes or exert control." A classic example is seen in JuG's tendency to answer most questions about what *he* cares about or desires by saying, "ask my brother," or "what do you think." People may suffer a loss of hope. When exposed to repeated experiences of being ignored or having to do as told, or "comply" with the rules of the facility and staff, individuals may simply stop trying to express their wishes. This is intensified for many people because of the dependency on the facility and on the staff for one's survival (i.e., people who cannot even get out of bed without help). In fact, people may not only stop being hopeful, they can even become fearful of making even the slightest complaint. As one expert noted: "Patients are frightened to complain about poor care because they are afraid it will affect any future treatment they receive…." (Calkin, *Nursing Times*). Studies in several different countries have found that nursing facility residents are reluctant to complain or state they are not happy with their care due to a fear of retribution. In my experience, this holds true as well for family members of people with IDD.

Authors/experts John Harris and Vicky White observed that *Learned Helplessness* is associated with a number of very debilitating outcomes such as anxiety and depression, and "has been associated with the effects of institutionalization." (Harris & White, p. 281). This is because facility-based care involves requiring that residents fit into the established routines, rather than having the individual select and determine preferred activities. This can occur in aggregate care of any kind, but the more people there are, the less there is any individual control. This is why group homes are designed to have just a few people, so that as much as possible, individual needs and preferences can be honored. It is also one of the foundational findings of years of experience with providing segregated care. This is yet another benefit of community living for individuals with IDD.

One thing I observed many times over my career were people living in nursing facilities and other institutions trying to please the caregivers and professionals, and say what they thought these people wanted them to say. This might include saying things like, "I am happy where I am," when every other indication suggests that really isn't true. In many ways, these effects of living in a segregated setting, with few opportunities for choice and control, are what people mean when they say a person has become "institutionalized." And the longer one is living in a segregated facility, the more this phenomenon is evident.

There are also concerns that people with IDD may not have many experiences making choices, or are often not asked for their views. Living in facility care amplifies the latter problem so that many individuals will just stop trying to assert what they believe, unless there is ongoing, intensive support for them to do so.

Another concern is the difficultly of changing the decision, once an (often difficult) "choice" is made. Why do people say they want to stay where they are when they are not happy where they are? Frequently, people have made a certain choice, and then become invested in their choice as having been the best one they could make (i.e., my loved one needs to be in a medical facility to have his medical needs met or community options are all bad like one we experienced in the past, so we choose to stay where we are). Then, when other sources (i.e., the Service Coordinator) state that there are facts suggesting the opinion is incorrect (those medical issues can be safely handled outside a medical facility, or there are very nice community living options), people may have a hard time hearing the new information when it is at odds with their previous choices. To overcome this, there needs to be a concerted effort to help people truly see what is possible. This can require a relationship in which there is trust. The constant turnover of Service Coordinators responsible for nursing facility clients can undermine trust and make it even harder for individuals with IDD to consider new options.

For anyone, when choices are important and difficult, it is always harder to choose change. Sparks et al. (2016) noted that people who have had difficult experiences making a certain choice will be more likely to avoid the selection if presented with the same or similar choice, because it is associated with negative emotional experiences. Other research demonstrated that, often, people will make “less-than-optimal choices … to avoid the prospect of future regret.” (Cella et al., 2007).

It seems critical that when it is hard to truly understand what a person wants, the default cannot be to remain in a segregated nursing facility. It is essential to document a range of efforts and activities that were done to ensure that people really make fully informed choices or that there really was no safe way for a community living opportunity to be created for the person. This is also important because of the usual challenges experienced by many people with IDD in learning new information, even when they were told and even when shown some photos.

Many people with IDD will have difficulty with time concepts, and other abstract concepts. Most exhibit what is called “concrete thinking,” understanding things only when you can see or experience them rather than understanding through verbal descriptions or hypothetical discussions. One impact of having difficulty with time is the inability to order and interpret past events, which can lead to reacting in the present as if it was the past. In discussing a future placement possibility, if there was any past negative experience, some individuals with IDD will have difficulty understanding that a new place could be very different (Owen & Wilson, 2006).

When teaching someone a new skill (i.e., to help a person acquire skills needed to live in a community setting or simply to increase their independence), it is well known that many people with IDD must practice that skill in all of the settings in which the skill will eventually be used, in order to generalize that skill. These findings have also been incorporated into PASRR regulations that state that active treatment is treatment delivered consistently across settings at all times, relevant to the acquisition of skills and the opportunities to practice those skills.

Sparks et al., 2016 noted that individuals with IDD “often require more extensive and direct instruction.” Many people with IDD require modeling, concrete experiences (seeing and experiencing things in addition to visual aids) and many repetitions, in addition to being provided written information or some photos to help them understand something “theoretical,” such as, you could possibly move to a different place if you want to. While the CLO process is supposed to include visits to community programs, I did not find anyone who had actually gone to see living arrangements or support programs. Also, there are many other “tools” not employed in my sample, that are commonly used in such situations, including showing people videos, inviting people to parties rather than formal tours, and linking people who have had positive experiences, to name a few.

Many people with IDD will not state that they did not understand what you have told them. This is because for many individuals we serve it is embarrassing and even traumatic to admit ignorance. Many people have been bullied and called “stupid.” It is important to ensure that an individual is making an informed choice and understands his or her options. In a few cases, the LIDDA Service coordinator, having documented that a person had declined a community living option, then told me or even documented that they were fairly certain the individual did not really understand their options.

VI. Summary of Aggregate Findings

In the course of the work I performed, I found the following for the 14 individuals I reviewed:

A. Comprehensive Functional Assessment

I found that none of 14 people that I reviewed had received a comprehensive functional assessment of all habilitative areas that accurately identified all of the individual's strengths and needs. Although many people received some assessments, including both a PASRR Level 1 screening and PASRR Evaluation, the standard nursing facility Minimum Data Set (MDS) assessment, and some other assorted nursing facility assessments, none of these assessments, when considered all together for an individual, were of the scope and extent of the types of assessments that I believe are needed in order to develop an informed and professionally appropriate ISP that meets the standards set forth above in Section V.

B. Specialized Services

None of the 14 individuals were receiving all of the necessary nursing facility and LIDDA specialized services, with the appropriate intensity, frequency, and duration, to address all need areas, in my opinion. Though I found people receiving some PASRR specialized services, there were very few in place. My review of these cases indicated that most all would have benefitted from having more of these services. In regards to the nursing facility specialized services of OT, PT and ST, it was clear that most of the nursing facility staff responsible for providing these services felt that the services were only supposed to be provided when a person experienced a decline and/or they predominantly relied on Medicare billing, which resulted in a lot of stopping and starting of the services. Very few people had services through PASRR that were designed or intended for prevention of functional decline and often, when skill building might have helped ready someone for community living or, at least, more independent functioning, the services were not in place with any consistency. LIDDA specialized services were also scant for those in the sample. A variety of issues were evident such as a lack of appropriate local resources, lack of access to transportation, misunderstanding what would be available in terms of medical supports at a day habilitation program, lack of available staff for programs like independent living skills training and other difficulties—all of which served as barriers to individuals receiving their needed LIDDA specialized services. A number of people I spoke with including the identified sample members and their staff readily agreed that the specialized services they were not getting would be helpful. A number of nursing facility and LIDDA staff stated that the importance of PASRR had somehow only recently been emphasized or that they thought it was because of our presence that they had been hearing more about it.

C. Active Treatment

None of the 14 people who I reviewed were receiving active treatment. This was related to a lack of continuous active treatment programs directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible. People simply were not being taught skills in an ongoing manner with target goals and review of the data regarding progress that is needed to indicate active treatment is happening. In several cases, people were described as being in bed much of the day. Active treatment programs were not designed to both maintain skills and functioning and prevent further regression to the extent possible in several cases as noted in the individual case reviews. When the PASRR services such as OT, PT and ST were viewed as only to be started after a decline, clearly preventing regression was not a consideration. Treatments were rarely provided across settings, such as the community.

D. Individual Service Planning

Of the fourteen people I reviewed, I did not find that any of their ISPs met professionally accepted standards. However, two of the individuals' records were missing the ISP in either part or in whole, and so I cannot reach a conclusive finding on this point for those two. None of the ISPs I reviewed were developed based on a comprehensive, person-centered assessment and included all needed services and supports to successfully transition to the community consistent with the professionally accepted person-centered planning principles described above in Section V.A. Few had meaningful goals and objectives. In fact, in most cases there was minimal reference to what the person would need to live in the community, as noted. Some assessment of areas that would address the person's key areas of need for growth in independence was conducted, but this was often very limited. In facility-based care, many things are done for the person that they might learn to do for themselves (or retain as skills they could do for themselves) and special efforts need to be made to compensate for this reality of institutional life. I did not see these efforts being made for most individuals.

E. Benefit from Community Living

I found that every person who I reviewed was appropriate for and could have benefitted from living in a community setting if such a setting was available with the appropriate supports, features and structure needed for the individual. A number of people had negative past experiences and had difficulty understanding or believing that a new individually developed community placement could be positive, appropriate and different from what they experienced in the past. Almost everyone I spoke with indicated some interest in learning about community living or opportunities to participate in community activities, and apart from one man, I do not believe any were really happy living in such a restrictive setting. For many, stating they were happy in the nursing facility was indicative of being happier than when in some alternative setting in which they had extremely negative experiences. Other barriers to community living included not having existing services currently available and in only rare cases, did the service planning team (SPT) consider how needed services might need to be built for a person. Per professionally accepted standards, ISPs need to address what the person needs, not just what exists and if not existing, then conclude the person should just live in an institution. Having a life in one's community is associated with a higher quality of life as it generally includes developing more social connections, more meaningful engagement and less isolation. There is greater opportunity for independent functioning when one is not in a segregated setting. Finally, there were 5 individuals, or more than a quarter of my small sample, who were young and especially out of place in the nursing facilities as they were many years younger than other residents. These individuals would all benefit from community living so that they could have opportunities to live with and interact with peers their own age. We all generally share interests more in common with people near our own age. Having most all other people we reside with be many years different in age from us is likely to result in social isolation. Examples of this were shared with me, such as the woman who longed to meet a man her own age and to develop a relationship. Even the nursing facility staff caring for young residents I saw shared that they felt these individuals were suffering from being segregated from their natural peer groups.

F. Informed and Meaningful Choice

Of the 14 people I reviewed, only one had made an informed choice to remain in the nursing facility. In the case of that person, it should be added that the guardian really was choosing the nursing facility that was near him so he could check on his nephew, over currently available group homes, after a bad experience in one in the past. Six people described negative past experiences in community placements. Except for one service coordinator, none of the service coordinators serving the fourteen people who I reviewed identified and addressed past negative experiences and other barriers preventing them from even considering a community placement. None of the assessments, apart from one case, provided a reasonable level of detail regarding how barriers to community living would be addressed or what the person would need to live in the community. In the one case where this was present, this was done only in older documentation by a service coordinator who subsequently left. At the time of my review, in no case did the individual have adequate assistance to address the barriers to community living. It is my opinion that these areas should always be covered in detail as they are foundational to the belief and the regulatory requirement that every effort is made to help people be able to live in more integrated community based settings, and not to live in institutional care settings. For example, in my review, I found that the ISPs contained either no description of the barriers to community living or, in some cases, only short phrases that only minimally described the barriers. In only one case was the person's ISP, section 9, phase II completed with a description of the person's transition needs, and in that case some of the identified options were inappropriate for the person. In regards to describing what a person needs to live in the community, it should be noted that often, people seemed not to really have understood what a life in the community could be. The service coordinator should have an understanding of the benefits of community living, and should be the qualified person to help the individual have a clear understanding of options, and ensure that the process of discussing and exploring this is informative and helpful. Doing so could help those individuals who simply did not understand how living elsewhere could be safe, beneficial, and result in a higher quality of life.

Five were people who had no guardian or needed decision-making supports and could not make an informed decision without some help or, in some cases, even with it. Five people actually stated to me they did not complain for fear it would lead to a compromise in care of their loved one or themselves, but were unhappy with current living situation. In none of those instances was there an active effort to help the person find a community setting when I first met with them. Additionally, in my review, I found that almost none of the fourteen individuals whom I reviewed were receiving the LIDDA specialized service of ILST that would have helped to provide them with opportunities to go outside the nursing facility and experience life in the community and learn community living skills. Access to the LIDDA specialized services provides critical opportunities to gain skills for community living, to generalize skills and to maintain skills that promote independent functioning. They do so far more than any services one could be receiving inside of a facility. Experiencing even some aspects of community life is helpful and could provide people with a more concrete sense of what a full life in the community could be, as opposed to simply hearing about options. Lack of transportation for people with large wheel chairs and difficulty identifying appropriate providers were noted as barriers to provision of these services to people identified as needing them.

In the case of 4 people it was believed that a community setting could not manage safe care in light of the person's medical or other challenges, when this is not true. In all cases, I found no visits to possible living settings had occurred. A number of simple steps could have been taken to help the people really understand what a life in the community might provide for them understanding when a person needed something more experiential or concrete than pictures and a verbal description briefly provided. In 9 of the 14 cases, the person or their guardian at some point stated they would be interested in learning more about and/or considering a community living option. Of these, two specifically expressed interest in leaving. This is in contrast to the documentation I reviewed, indicating that all of the people I went to see and/or their guardians had stated they had no desire to do so.

VII. Individual Findings

SH

Date of Visit: August 22, 2017

I reviewed the records that were provided, and interviewed SH, her LIDDA Service Coordinator, her Nursing Facility LVN and Social Worker.

SH is a 50-year-old woman who has Cerebral Palsy. She has been at the facility where I interviewed her since April of 2017. She shared with us her journey from living with her parents for 43 years, and from walking with use of crutches and braces, to now being dependent on a wheelchair for independent mobility and residing in a nursing facility. Following her parents' death, she stayed with her brother for a short time. This is the fourth facility move since then. She moved to her first nursing facility after a hip replacement, after which, she needed to use a wheelchair. She then became more depressed, and had a behavioral health inpatient hospital stay. She was admitted to her current nursing facility directly from the hospital on 5-31-13 because the group home that she had hoped to move to, and which had initially accepted her, then declined to serve SH because they determined that they could not meet her needs because of she has a remote history of seizures.

SH is an extremely bubbly, warm individual who is described as always "eager to try new things." She enjoys fashion, is very stylish, very religious, loves meeting new people and enjoys outings and community activities. She hopes to eventually have a special relationship with someone, and described how people with disabilities can find love too. In her IDT/ISP, "people in individual's life" include only her Service Coordinator, who is a strong advocate and who has been her service coordinator for several years. SH is treated for depression and anxiety. She has Gastro-Esophageal Reflux Disease. Though SH needs help with transfers and basic care due to her mobility challenges, she is fiercely independent and retaining as much independence as possible is clearly vital to her. When I spoke with SH, she laughed and smiled and demonstrated a great sense of humor. However, she also expressed much sadness about the limitations in her life, and admitted these get her feeling down at times. She has been unhappy and bored living in nursing facilities. SH described feeling misunderstood at times and wants to be respected for her strengths, and not labeled or defined by her disabilities. This is so important to her and experiences that emphasize her challenges have been traumatic for her. She wants to be around people closer to her own age.

During our meeting, SH explained that she has wanted to have PASRR OT and PT, but that she was told "no" by the former facility rehabilitation service staff and then again, by the staff at her present nursing facility, until very recently. However, I found a document that indicated she was receiving PASRR OT services in March of 2017 just before she was discharged to her current NF placement. She will apparently be getting the needed specialized services soon, but only after a lengthy time without these services, and with much disagreement over whether or not she should be provided with them, as documented in her 2017 IDT/ISP meeting notes. After discussions during which SH stated her disagreement with the nursing facility's denial of specialized services and her wishes for the PASRR specialized services, SH asked her SC to file formal complaints against the nursing facility for failing to provide her with specialized services. After these complaints were filed, SH was eventually approved for PASRR OT and PT. The approval letters arrived on the day of our visit. SH was very proud of herself for advocating for the PASRR specialized services, as she feels she really needs it to decrease stiffness and feel stronger (she explained that she really feels the difference when she is getting these therapies).

It is my impression that SH did not receive a comprehensive functional assessment, despite receiving some assessments. In my experience, a comprehensive assessment would include assessments of all habilitative areas that accurately identifies her strengths and needs. The evaluation (and documentation of it) should have indicated many of the things that I was able to glean in my conversation with SH about her personal strengths, needs and preferences. Especially key would have been a detailed discussion of the barriers to her achieving goals she has expressed. She wants to be as independent as possible, to be more involved with people her own age, to be going to church and to be out in her community contributing and benefitting from such opportunities. Despite this, her Care Plans and ISPs do not include all of the needed assessments to inform an appropriate ISP. Areas that were not addressed included behavioral assessment, assessment of her affective needs, assessment of her sensorimotor development, assessment of her independent living skills for community life, communication needs and social development. Her earliest PASRR Level II Evaluation in 2013 recommends PT and OT and only service coordination from the LIDDA. A later PASRR Evaluation in September 2015 recommends no specialized services except service coordination. In April 2017, a PASRR Evaluation again recommends PT and OT along with service coordination and alternate placement services, and another PASRR Evaluation the following month adds DME to this list. Finally, a PASRR Evaluation conducted in July 2017 recommends only DME, service coordination and alternate placement services. She did have an initial OT and PT assessment through Medicare, and as a result received short- term interventions, but these were discontinued.

SH had a stated goal at the time of her initial PT assessment dated April 25, 2017 to get stronger and to be able to walk farther. Her PT assessment reviewed risk issues as follows: “Without skilled therapeutic interventions, the patient is at risk for: contracture(s), decrease in level of mobility, decreased participation with functional tasks, falls, further decline in function, immobility, increased dependence upon caregivers, increased tone, limiting functional movement, muscle atrophy, pneumonia and pressure sores.” Services were provided through Medicare Part B and she was transitioned to “restorative” services after only a few weeks of skilled therapeutic interventions. OT was provided through Medicare Part B as well, and was short term, despite SH asking for ongoing habilitative care. An undated Care Plan (handwritten) demonstrated how little the team was attending to SH’s expressed wishes, preferences, needs and interests as it included one sentence about helping her stretch in restorative services so she can put socks on, and another goal that she can do activities by herself like coloring and talking to other residents.

The Nursing Care Plan note covering the period of April 21 to June 21, 2017 seems disconnected from the ISP process. Goals listed in the Nursing Care Plan included doing an activity of her choice 2 times per week, skin care, maintaining her nutritional status, staying “clean,” free from pain, free from infections, and free from side effects of her antipsychotic drug and antidepressant drugs. There is a goal for her to be free from distress and depression, and it is noted that to address this goal, it is important to provide her with activities that are meaningful and of interest. Yet activities of interest to her have been quite limited such as being able to get to the church to which she belongs, meeting a man her age with whom she might develop a relationship, going to community based social events and going out to eat with friends. Maintaining her current level of function in terms of independence in her self-care was noted to be “resolved” In May 2017. This is at the core of her dispute with the facility, as she had clearly stated she wanted PT and OT PASRR habilitative services, and she stated she felt better when she had these previously and wanted to have them again. None of the care plan goals address her actual interests, to work on building strength through OT and PT, and to be with people her own age, to be able to go to her church in the community, to be out and about more, to have the chance to meet someone and maybe develop a relationship and to be as completely independent as possible. Her interests in fashion and style and religion were not integrated into her plan at all.

As of the day of my visit, SH had not yet received the necessary nursing facility or LIDDA specialized services that should be available to her under PASRR in her current nursing facility. She received a letter indicating PASRR services she had requested were approved the day of my visit. She may finally begin to get some of these services, after she and her SC advocated vigorously for her to receive them; services she was forced to file formal complaints to secure. Some of the barriers to her receiving such services appear to be systemic in nature, as reflected in my discussions with various parties and included unavailability of transportation, and lack of placement options locally with adequate resources to meet her needs. Of most concern is the possibility that the lag in providing her with specialized services could have contributed to loss of strength and even skills or abilities, based on her own description of how much stronger and better she has felt when she received the direct OT and PT skilled services. Also, she was reportedly able to walk at some point early on in her journey through a series of nursing facilities, as per recollection of her service coordinator. It was also surprising that she did not have LIDDA specialized services of vocational services or community living skills (independent living skills). It was clear that SH had misunderstood several things. She stated to me, for example, that she had thought that she could not get PT and OT in the community, that she would be unable to contribute adequately in a vocation of any kind due to her disabilities, and that she might be put in a workshop and be unable to keep up. She also seemed to think options for her would always and only mean living with people with intellectual challenges and who were not at all like her. These barriers were not elaborated upon in her CLOs, despite there being a section in these forms where this can and should be addressed. No specialized services were listed in the most recent ISP dated June 21, 2017.

Everyone apart from the Rehabilitation department at the nursing facility agreed SH needs PASRR PT. I also believe she would have benefitted greatly from ILST services to help her experience being active in her community and be able see for herself that she can do this. This could help her prepare for community living and increase her independence. She could benefit from vocational services and community living planning services. She might also benefit from behavioral therapy to address her low self-esteem and provide cognitive behavioral treatment of her depression, rather than depending on medications when her sadness has been about real issues like living with people who are older than her and hardly ever getting out of the facility. No specialized services were listed in most recent ISP dated 6-21-17. A goal written by her service coordinator was for SH to keep getting therapy to get stronger, but no therapies are listed in her ISP. According to a note from her service coordinator in SH's 6-15-2016 ISP, although SH's SPT, including SH, agreed that SH should receive PT through PASRR, the NF Director of Rehabilitation refused to provide SH with these specialized services, because the DOR believed that therapies could only be provided if a decline in functioning was identified and not to maintain functioning. In 2016, SH received Medicare funded PT but was discharged from this on 9-22-16. Discharge recommendations were listed as "home exercise program." Therapy (OT and PT) initially provided at the current facility was through Medicare Part B and was discontinued on 6-26-17 because she allegedly met her goals. The nursing facility did not believe SH needed OT and PT through PASRR and the service coordinator disagreed. SH told the IDT that she can feel the difference when not getting PT, and that she feels stiffer and weaker. The nursing facility also wanted her to use a Hoyer lift, because a recent state review showed that it was not safe to transfer SH via a 2-person lift. However, SH felt very strongly that a Hoyer would further take away her independence and stated she did not want to use the lift.

I interviewed the NF Social Worker and asked about her understanding of recent events related to PASRR Specialized Services being sought for SH, and her general understanding of PASRR at the facility. The Social Worker explained that she had only been employed at the facility since July of 2017 (only about 6 weeks). She was aware of PASRR and understood that there are habilitative and rehabilitative services one may obtain (PT, OT and others). She seemed less clear that it is not a necessity that Medicare be exhausted to use PASRR to provide OT, PT, ST or any of the PASRR nursing facility specialized services to a person who has IDD. She said yes that can happen but, the usual process is that services like OT and PT use Medicare part A, then B, then can transition to PASRR. She did not know what PASRR services SH had. She was aware that SH's Service Coordinator had filed complaints, and described this as having provoked an adversarial relationship between parties that need to be collaborating to promote optimal care for the resident. I was concerned that it was her perception that the SC filed formal complaints without telling anyone there was a problem or concern. This is simply not the case, as stated above, there was open dialogue about the dispute. This is well documented in SPT notes, written by the SC.

Based on the above, it is very clear that SH would benefit from receiving more specialized services. She has only $60.00 per month and would have to get her own way out to church, but this might have been possible with assistance through ILST. She does get some transportation to community activities from the NF, but this is limited. If she attended a program or had a vocational opportunity, she could potentially be doing things provided as part of the programming that she has to purchase for herself now. It was shared that one bus to activities she wasn't allowed on because it was not equipped to take her wheelchair.

Based on the above, I do not believe that SH is receiving a continuous active treatment program. It would be important for her to have a program directed toward the acquisition of the behaviors necessary for her to function with as much self-determination and independence as possible, while she now hardly gets out of the facility. The need for services that are designed to maintain skills and functioning and to prevent further regression to the extent possible clearly was not provided as of when we met with her, nor for some time prior to that, except intermittently and through Medicare (not PASRR). This has restricted how much service could be offered. Nursing facility staff then are unlikely to be supporting and helping her generalize skills built into these services (to use any new skills she acquires across all of her day and not just during a therapy session), since these services were not provided to her consistently or at all.

Based on the above discussions and records reviews, it is my impression that SH did not receive a professionally-appropriate ISP. Appropriate and person-centered ISPs are based on comprehensive assessments and as noted, her assessments were limited and not comprehensive. Also, as noted, the ISP and Nursing Care plans were not integrated and addressing SH's expressed preferences or interests. The goals were not really person-centered as noted, because they simply left out things SH wanted when the NF disagreed with her or when it might be difficult to secure something (i.e. lack of transportation). Regulations clearly state that the ISP should include what is needed for the individual, regardless of availability.

I believe that SH would benefit from having an opportunity to reside in a community setting. Her SC, her SW, and she herself all attested to this during our interviews. In contrast, her CLO forms dated 6-21 and 6-29-17 state that she does not want to leave the NF. Within these documents, there was no explanation of why she was stating that she does not want transition to the community. Why would this be her response since she states she is unhappy and bored, wishing she could do more and be in her community? This was also the case despite having a very concerned and active SC, who in our discussion with her recognizes SH would be better off in a community living option. SH's service coordinator mentioned that she has been ambivalent about moving out of the facility. In my experience, it may be unusual for anyone contemplating a major move like this *not* to have some anxiety, but especially when one must depend on others for things as basic as getting out of bed. Also, it is difficult in a group meeting with caregivers upon whom a person relies for the most basic of needs like this, to state that you don't want to stay in their care. In fact, SH said at one point, "[s]ometimes it's better to keep your mouth shut." Often, in my professional experience, people with disabilities fear speaking out and complaining when life at a facility feels restrictive, or when there are problems, or even just that a person might not be happy and may want to leave. When I clarified some things for SH (i.e. that she would not have to work in a sheltered workshop setting and that she could get medical help in a community setting), she was enthusiastic about looking further into a move to a community setting. Most of the documentation in her records and her history also support that she wishes to be much more active and to be involved in her community. She is a vibrant young woman who has a future and has hopes and dreams, most of which are highly unlikely to be fulfilled living in a nursing facility with primarily much older people, and with minimal community access. The fulfilment of these hopes and dreams are more possible if she can be out and about in her community, with appropriate services and supports. Unfortunately, in the records I reviewed, I saw no documented description of what she would need if she decided to opt for considering a placement, something that proved to be very important to the actual decisions she has expressed.

I am convinced that SH did not make an informed choice to remain in a segregated nursing facility.
SH's concerns and barriers to community living were not fully documented or addressed
Yet, we were able to discuss these with her and her SC. Based on her responses, and those of her SC, it seems that previously SH was making decisions based on false beliefs about what a community living option would entail. Based on my experience, it is my professional opinion that it is important to describe for people not simply the type of house or set up only, but what really are possibilities for what life might be like living in the community. This is especially important in regards to accessing activities and social opportunities not as easily available in a NF. SH, for example, wants to go to church, do arts and crafts activities, maybe meet a single man her age and other things to which she has extremely limited access to while living in a facility.

According to her SC, a barrier for SH to transition to the community in the past has been lack of appropriate openings in settings that would meet her needs in the area within which she would like to live. She has had a boyfriend and a pastor (and church is very important to her) in this area. Her SC explained that there generally are very few HCS supported options with openings at all, never mind ones that would likely be a good fit for her, in an area where she wants to live. Despite this, SH agreed she wanted to hear more even regarding locations a little farther away from where she wants to live. Another barrier has been that SH does change her mind because she is anxious approaching this type of decision. SH apparently did not understand that she could still get PASRR types of service (OT and PT) in a community setting. SH mentioned a couple of times that she really did not know what it would be like if she moved into the community. SH shared how she feared she would be sent to a program and be unable to do the activities or do work in a workshop type of program due to her disabilities (none of which is true). She worried she would be placed with other people with whom she could not converse (yet she would be able to decide about any potential placement, visits etc.).

After our discussion, SH stated that she wants to "go for it," though she is nervous. She needed reassurances that she would not have to do this in a rushed manner and there could be time for planning, and she needed help understanding some of the realities of these options (what her life might be like in a community setting). She really wants to be out in the world and her access, even to getting to church or other community activities, has been very limited in the NF. She is very religious and she needs to be in a group or host home or residential placement in which she would be able to be out and about a lot and get to church. She said she would love to just go to a bowling alley and watch even she cannot play herself. She loves getting her nails done, eating out, helping others and she really would love to meet a man and develop a close relationship, even get married at some point. She recognizes that she would likely have more social opportunities in the community.

Her SC said SH lost ground (regarding her movement, mobility and strength) since she has lived in the various NFs. She reported that she met her in 2014 and at the time, she still was able to walk some with specialized crutches. Failure of the NF personnel and the SPT to facilitate her receipt of consistent PASRR SS may have contributed to diminished strength that would support her independence. Her SC had said that a Host Home can work even for people like SH who may need a lot of assistance but availability in the local area that has been a challenge. SH did say she would consider the city nearby though that isn't her preference. As noted, these details were not documented and there was no indication that meaningful efforts have been made to remove and address barriers for SH to live in the community.

TM
Date of Visit: September 6, 2017
I reviewed records provided and visited with and interviewed TM, her Service Coordinator, the LIDDA Supervisor, the nursing facility MDS coordinator, and the nursing facility rehabilitation director.

TM is a 28 year old woman with developmental disabilities who resides in a nursing facility in Texas where she was admitted in May 2016. Prior to being admitted to her current nursing facility, TM resided in three other nursing facility placements, including one immediately prior to the current facility. She seems to have been moving from place to place and disliking each of her experiences in nursing facilities. She also reported having delays in seeking community options related to surgery. In the past, TM lived with her mother, with whom she had a highly conflicted relationship. She had multiple hospitalizations, and lived on her own with an abusive boyfriend for several years. At age 14, TM acquired transverse myelitis caused by an infection leading to paraplegia, secondary to lupus (a major autoimmune disease), resulting in her developmental disabilities. By her report, the signs and symptoms of the dangerous infection were missed and treatment delayed that would have prevented her current severe disability. She suffers from numerous related medical problems in addition to paraplegia. She has muscle spasms, edema in her legs, Gastro-Esophageal Reflux Disease (GERD), irritable bowel-constipation, chronic pain, recurrent urinary tract infections, and pressure ulcers. She uses a wheelchair and needs significant help to complete daily living skills. She had a recent colostomy, followed by an infection and sepsis, and now needs the colostomy to be revised due its inappropriate placement. She also has several psychiatric diagnoses including Bipolar Disorder, Borderline Personality Disorder, and Schizophrenia. She takes many medications, including psychiatric medications and an antipsychotic, though her symptoms are described as mainly reflecting problems of anxiety and depression. TM repeatedly stated that she is very unhappy residing in the nursing facility and wants to transition to the community as soon as possible because she feels isolated and wants to live with people in her own age-group. During my interview with TM's Service Coordinator, he shared with me that he felt he probably should have tried to divert her from nursing facility admission before, and wished he had worked more to secure a community option for her.

TM has a vibrant personality, loves art, and is quite talented. She enjoys reading books (especially fantasy). She has a sharp, self-deprecating and sarcastic sense of humor. She is stylish and cares about looking stylish, and being an independent young woman. She reported that living in the nursing facility has been very depressing and difficult for her, as she is primarily with much older people. She described the nursing facility as "jail for old people," and described how she often feels that staff at the facility do not believe what she says. She stated that the best thing to do here is to "keep your mouth shut." She understandably expresses a great deal of frustration with the course of her life. Her humor, creativity, and resilience are her strengths. Her hope is to be able to leave the nursing facility and live in an apartment with some supports. A short-term wish is to go to a Renaissance Fair, but TM's dream is to become an illustrator, video-game designer, and entrepreneur. She shared some of her artwork which was very good, and she brightened when discussing this. She seemed to doubt me when I honestly shared how funny and interesting a person she is. The sadness underlying her "tough talk" and stories of rebellious activities was palpable. However, she also is a feisty character who has survived significant trauma. On top of all of the above, she has had pets (two different service dogs) that provided comfort to her and she lost both of the animals (one was removed from the nursing facility and the other killed by a car).

TM did not have a comprehensive functional assessment of all habilitative areas that accurately identified all of her strengths and needs. She had the usual nursing facility assessments including the MDS, daily nursing care needs, and medical needs assessments, but did not receive the scope and type of comprehensive assessment that one would typically see developed to inform an individualized, person-centered ISP. Although TM's nursing facility care plan stated that she had initial physical therapy and occupational therapy evaluations, the latter had limited details regarding her abilities for self-care. I did not see a behavioral assessment (though there is a one page plan), or an assessment of her social development needs. As of May 16, 2017, ILST was planned and an initial assessment was expected but had not yet occurred. An assessment was not completed for the annual ISP dated June 1, 2016. Her PASRR Evaluation dated 5-26-16 recommended Service Coordination from the LIDDA and CMWC and Specialized OT, PT, and ST from the NF. It subsequently took until November for her to get the CMWC, and OT was only provided off and on. Another PASRR evaluation, dated March 21, 2016 recommended only Service Coordination and a determination of ID. The ISP/SPT update August 29, 2016 which appears to be the next meeting of the SPT after the annual review, was the same date as the IDT. The IDT form, however, is missing every other page in the document. However, it should be noted that on the August 29, 2016 IDT, the ILS which was recommended in the team discussion at the annual is not checked on page 3 where recommended LIDDA SS should be indicated. It was suggested that she would need OT to work on maximizing independence and strength in June 1, 2016. Then in August 2016 (in Section 9 of her ISP/SPT updates, page 8, Phase 1 Transition Plan), it is documented that there was an "OT assessment deletion." This was reportedly because "Therapy feels consumer is most appropriate for Rehab therapies and does not meet definition of habilitation therapy at this time." Page 9 is left blank. This is important given that TM so wants to live in the community and it would seem important to assess her current status specifically with respect to what an effective setting and services would need to look like to meet her needs. This then could be used to develop an effective ISP and point to exactly what is most needed for immediate work to help her transition into community living, as soon as feasible since she clearly did not enjoy her life in facility based care. There was finally some documentation of what she would need in the community I was able to find in her ISP dates 2-5-17, which was the first documentation I could find of the Phase II form being completed. A boarding home or HCS RSS, which could be a group home or host home, is listed though TM has repeatedly stated she wishes to be in an apartment with assistance.

Her nursing care plan document which contains updates through May of 2017, has only minimal and vague references to how TM will be helped to prepare for a life in the community. An actual goal was for her service dog not to bite people. There was one goal to explore what to do to help her go to school or get a job, but no real plans on how this would be accomplished and no reference to LIDDA specialized services for this. The majority of the goals were related to medical/nursing needs. The plan is not person centered or clearly linked to her stated goals of wanting a life in her community, apart from the one goal noted here regarding a job or school. There is a SC note dated 8-31-17 that did include ILST continuing, and also employment assistance but it seems this ended up on hold until she recovered from colostomy surgery.

TM was not receiving all necessary PASRR LIDDA and nursing facility specialized services with the appropriate intensity, frequency, and duration, to address all need areas. There were multiple PASRR Level 1 screening forms provided. As stated above, her PASRR Evaluation dated 5-26-16 recommended Service Coordination from the LIDDA and CMWC and Specialized OT, PT, and ST from the NF. A 5-16-17 PASRR SS Form listed no NF SS and ILST and employment services as the only LIDDA SS apart from service coordination. I cannot establish whether the initial PASRR Level II recommendations for specialized services were discussed at her initial IDT because there are missing pages in the June 2016 IDT.
Of the nursing facility specialized services, a Customized Manual Wheel Chair (CMWC) was recommended in the ISP annual meeting dated June 1, 2016 and then significantly delayed. It had not yet been obtained as of August 29, 2016, but seems to have been secured by November of 2016. It appears that DME was recommended at the initial meeting of the SPT/ISP planning on June 1, 2016, to secure a support mattress, which then was eventually done by August 29, 2016. She had OT through what I suspect was PASRR funded OT (Medicaid is listed as the payor) in 2016 between June 2nd and July 27th, and then a discharge summary stated she had reached her maximum benefit of this service and it was stopped. OT appears to have been provided again October 7th to November 21st, 2016, and February 21st to May 19th 2017. Her November 2016 ISP update, CLO dated November 17, 2016, reported the same barriers as earlier versions of her ISP page 9's but it was also stated that she was determined to not need skilled OT services. Her only PT services included an initial assessment on June 23, 2016, during which TM's status was marked as "restorative" with no follow-up. In this document, it was stated that she is "not an appropriate candidate for skilled PT as she is at her current baseline status." TM should have received physical therapy and both PT and OT services should have been ongoing and habilitative, rather than time-limited, because of her physical challenges and the need to prevent loss of strength. This was critical to her as she so values her independence. A PASRR SS Form dated 4-28-17 indicated she had no need of any NF SS.

As to LIDDA specialized services, she did receive behavioral services. Her May 16-17 ISP team meeting indicated "the team decided" to stop these services because she had psychology and psychiatry services. Having a therapist would not obviate the need for behavioral services. It was at this meeting that TM asked about getting the employment assistance though she had discussed this before in meetings with her SC (note dated 4-29-17). ILST services were recommended and were significantly delayed. As of November 17, 2016, she still did not have ILST due to volume of requests for these services (and apparently, a lack of availability of providers). ILST did eventually start, and though I did not find an exact date in the records, she had them as of a February 2017 SPT quarterly review note but then had lost them as of May 2017, with a plan to get them back in place, which occurred in June 2017. There was a note from 7-24-17 when TM's dog died, the ILS person came and took her out and was very comforting to her. In the course of their time together, TM reported having recently had to sit in a "BM diaper" for 2 hours. TM reported enjoying the ILST service. Her ability to be out in the community seemed limited, however, as the ILST is for just a few hours per month. The May 16, 2017 quarterly review note stated that ""interactions in the community have been limited to what outings the facility is able to accomplish." In her ISP note dated April 28, 2017, it was reported that "I desire to have social interactions with persons my age, including dating." She apparently meets people online but I did not see documentation of how her team would support her finding other ways to meet people her own age and other ways to be involved in her community, even though such socialization was one of her stated desires and goals as well as crucial to her progress. PASRR SS Form from November 2016 listed the following SS: NF- None; LIDDA –

SC, Employment Assistance and ILS. The PASRR SS Form from February 15, 2017 listed the same. PASRR SS Form from April 2017 indicated she should be receiving LIDDA SS of Service coordination, ILST, Employment Services and Behavior Support. A note dated 8-31-17 written by her SC provided an update and noted that TM was receiving ILST still, but also employment assistance, though it was further stated that employment assistance services had “faltered” due to staff turnover.

The above-noted services are insufficient. TM’s nursing facility records indicate that she is also experiencing changes in her condition that affect her swallowing, and yet she does not have a current plan to address this decline in her functioning. Additionally, although the nursing facility records identified certain behavioral problems, it was concerning that there was no plan or guidelines for the nursing facility staff on how to best support TM in learning positive alternative coping skills and to learn independent living skills. Instead, when TM shared her frustration with life at the facility, her behaviorist told her to make the “best of it” until changes are made, and that she needs to convey concerns in a calm manner. Like many traumatized people, TM says things and does things that are likely manifestations of her very real frustrations, discomforts, and challenges but also sometimes represent poor coping with a terrible set of traumas. In my discussion with the MDS Coordinator and the social worker, they openly referred to her as “a spoiled brat.” A March 27, 2017 Service Coordinator note documented a call from the facility MDS coordinator regarding a psychological assessment, stating that TM was “making a big deal” that she is a “genius” and should not be placed in a group home with others who have cognitive challenges. Based on my interview with the staff and on my review of the records, there seemed to be a lack of appreciation for how hard it has been for TM, and how difficult it is for her when it is assumed she is cognitively challenged because of her physical and developmental disabilities. She has also expressed a desire to take more courses at college and also to get a job and should have had employment assistance. I also note that the nursing facility staff has no understanding of PASRR and of habilitative services. The Rehabilitation Services coordinator stated that she believed habilitative services referred to when a person needs to learn a new skill, while the MDS nurse stated it meant, “To work on a separate goal.”

Given the above, I do not believe TM has been receiving active treatment. As described above, she did not receive a comprehensive functional assessment and she was only having specialized services off and on. The services she did receive were not provided continuously and consistently nor were they designed to promote independence and prevent regression. TM would have benefitted from ongoing behavioral treatment services that were more focused on her developing skills for community living. I did not ever see a functional behavioral assessment or detailed description of the behaviorist’s clinical views regarding why TM might at times resists NF staff directives. Rather, a behavior specialist (BCBA) note dated December 28, 2016 suggested she (the BCBA) would be checking with the NF staff to see if there were any behavioral issues, and another note dated December 13, 2016 where she advised TM to ask for her bath calmly. A note from January 31, 2017 from the BCBA indicated that TM eats alone in her room and is isolated, but does not indicate a plan of approach, guidelines for NF staff or other standard approaches that would potentially have provided some remedies to the documented concerns. TM’s BCBA did develop a Behavior Plan which is one page and outlines how staff should approach her and react when she has periods of being distressed and engaged in “verbal disruptions.” I could not find the Functional Behavior Assessment on which it was based and it did not include a review of antecedent controls based on such an assessment, or what new skills she might need help to acquire as replacement behaviors. Some of the staff directions did imply that her verbal disruptions would be more likely to occur if staff did not approach her in a particular manner (using a calm voice for example). TM dropped the behavioral services in May 2017 according to the SPT note. TM had limited assessments, followed by a very limited ISP without having a structured daily routine within which her goal for getting to live as independently as possible in the community was being addressed. To engage her in active treatment, it would have been necessary to develop a plan of activities that incorporated aspects of her preferences and interests. She communicated that she did not like most of the activities offered at the NF. It seems reasonable and likely that most 28 year olds would not be interested in activities at a nursing home. It would have been important then for her IDT to consider how to provide active treatment by developing a schedule of activities more suited to her needs, especially community based activities. However, documentation included comments as noted above that "interactions in the community have been limited to what outings the facility is able to accomplish." A note from 7-25-16 documented a Mental Health clinician suggested to her that she try "getting out of her room at least a few times per day." Clearly, she was not actively engaged in a program.

TM does not have a professionally-appropriate ISP that was developed based on a comprehensive, person-centered assessment that includes all needed services and supports to successfully transition to the community. The ISP documentation I reviewed was from June 2016 and April 2017. As described above, there was no comprehensive set of assessments that were incorporated into the ISP, or elsewhere. Most striking was the fact she was not provided with individualized transition planning assistance, despite it being clear to all that she should be living in the community and wants to be living in the community. Her staff reported she sometimes changes her mind, but should recognize that it is frightening for her to take these steps and that she needs reassurances and supports, and clear information about what a life in the community would look like. Her ISP had elements in it working towards this goal, but they were not complete or comprehensive. At her June 2016 ISP, she stated that "It is important to me to move towards my goal of living on my own." Despite this, section 9 of her ISP, where the team or service coordinator define what supports are needed for her to live in the community was left blank. Documentation in the June 2016 ISP suggests that her team sees her expressions of frustration with her life and disabilities as a manifestation of mental illness, stating she "…needs assistance with ADLs and proper social skills at times." Section 9, where presentation of the CLO is documented, and barriers to living in the community are supposed to be described, recorded that the barriers for her to return to the community were her mental health concerns and needing time to become healthier, neither of which seem reasonable as barriers because mental health and physical health care services are or should be available in the community. The need to wait to pursue an apartment also did not seem reasonable, since the only explanations given were that it might be difficult to find apartments that were accessible for a person in a wheelchair, and she would have to wait for availability of low income housing. Her Service Coordinator stated to me that he feels now that he should have been more aggressive seeking a community placement for her. In the April 28, 2017 nursing care plan conference, there is a difficult to read handwritten note without much detail, noting she wants to leave the facility, wants to go to school, and eventually to get a job. This is also listed in her ISP of the same date. Page 8, where there should be a detailed plan regarding what she would need for her CLO, is blank.

When she expressed her most important goal was to live in the community, it was documented that, "It was noted that it could be a couple of years before low income housing is applied for." As noted, her SC seems to regret having taken this stance. As described above, documentation of what she would need in the community finally appears in her 2-5-17 ISP, where Phase II of the transition plan section is completed, but this does not appear to contemplate placement options consistent with TM's desires, as they are limited to boarding homes or residential HCS placements. I could not find any June or August 2017 updates to her ISP or an updated IDT form.

TM would benefit from living in an integrated setting with appropriate community services and supports. She could be adequately and safely served in the community. I did not understand why there was such a long delay in finding her a place to live, though the delay now is related to her need for a follow up surgery to a colostomy she had. She wanted the colostomy to reduce her having to be assisted to the toilet frequently in order to increase independence. However, the placement of the colostomy was problematic as she cannot clean the area due to how it was situated in an abdominal fold. She had an infection and sepsis after the surgery and all of these complications have caused a delay. On February 15, 2017, a nurse who seemed to know her well shared concerns that "consumer's social needs are not being met in the Nursing Home and that the facility limits her psychosocial development." She strongly suggested consumer consider community placement. They then reviewed HCS options, stating that TM was open to explore. Other nursing facility staff reported that TM changes her mind about leaving, though she seemed very firm in this desire when I spoke to her. It is not documented whether any efforts were taken to address the reasons for her changing her mind. Based on my conversation with TM, she expressed she is mostly concerned about the nature of what settings would be available to her. She would not want to move with people with significant cognitive challenges, but stated she would need roommates due to costs. She has somehow concluded that she would have to have a roommate or she will not be allowed to leave and reside in the community in any situation except to live with people who are very different from her and with whom she would have difficulty relating. Often, people who have physical and developmental disabilities but not cognitive disabilities are treated as if they are intellectually challenged. This becomes a very sensitive area. I believe that training in trauma informed care and working with people with various types of disabilities provided to caregivers, would be helpful for many individuals like TM. Finding a wheelchair accessible apartment was also discussed as a barrier.

CLO forms such as the one from November 16, 2016 indicated that TM had to wait to start the process of finding a community setting and indicated that her mental health was a barrier. Further, it was unclear why her preference for living with supports but in her own apartment was seen as a long-term goal and why it was not pursued.

The SC note dated 8-31-17 included the most discussion of any document I reviewed about community placement plans. However, it seemed as if the discussion was back to the beginning, talking with her about group home options, that she needs low income housing and accessible space if she gets an apartment. I did not find reference to her having ever been placed on a wait list for low income housing or for a wheelchair accessible apartment since these things were discussed one year ago. TM again expressed her hope to reside with someone near her own age if she was to move into an aggregate care setting. In his 8-2-17 note, the SC stated that it was not likely possible for her to live on her own with supports, which is her preference, but not why this cannot be worked out for her. There earlier discussions that at least mention community options, such as at the February 2017 ISP update meeting, but these discussions never seem to be translated into actual plans.

After reviewing her medical record and speaking with her in person, it is clear that TM has not made an informed decision to remain in the nursing facility. She expressly wants a life outside an institutional setting. She has consistently expressed her strong desire to leave the nursing facility and to enjoy the benefits of a life in the community. Even her nursing facility staff recognize that TM has not received assistance to address her needs, and her fears about, or barriers to living in the community. Everyone I spoke with agreed she would be happier if living in a community setting where she would have more access to people her own age, and activities of interest to a person her age. Her Service Coordinator admitted that more should have been done to expedite her having an opportunity to move out of the facility. TM has suffered and continues to endure emotional pain from the lack of aggressive work to support her in meeting her goals to have friends her own age and a life in her community, with opportunities based in her strengths.

BT

Date of Visit: August 21, 2017

I conducted a review of available records, an interview/observation of the individual, and interviews with his mother, nursing facility staff (a Licensed Vocational Nurse (LVN), Physical Therapist, ADON, MDS coordinator, and Rehabilitation Director), and representatives from the local LIDDA (Diversion Coordinator and Program Manager).

BT is a 53-year-old man who has significant congenital motor symptoms, intellectual disability, and a diagnosis of Cerebral Palsy. He has a history of and takes multiple medications including two for his seizure disorder. He has major challenges to his ability to communicate, needs significant daily care, and uses a wheelchair. He has spent most of his life in facility based care. BT's Resident Admission Record from the Arlington Residence and Rehabilitation Center, dated June 12, 2017, states he was admitted to the current facility from a hospital in July 9, 2010 (unclear if he was hospitalized from this facility or elsewhere. His mother reported that he has been in various facilities for most of his life. He has been at the current nursing facility for either about 7 or 10 years (the records indicate different entry dates of his time in the nursing facility). Most of his caregivers described him warmly as someone who smiles a lot when with people he enjoys. He loves watching movies and Little House on the Prairie. He enjoys some activities at the facility, but mainly he will sit in the "sun room," and seems to enjoy watching the people going by, greeting the ones he knows. He has a very loving and devoted mother whose health is declining. She expressed concern that her son may suffer due to her being ill and unable to be present at more of the meetings and to check up on him. She has seen his functioning decline over his years in the nursing facilities and over his life. There also has been turnover in the nursing facility due to ownership and management change and turnover in Service Coordinators (three in just two years and yet another to be identified presently).

When we arrived at the facility, BT was in bed and there was a strong odor of urine. He had facial stubble (something his mother told me she does not like). He had visible scratch marks on his hand and behind one ear, and his nails were long and possibly sharp. His hands were very contracted (tight fisted posturing was clear). His mother reported the extent of contracture of his hands has been longstanding but has been worsening over the years. She recalled how she would place face cloths in his palm to prevent the tightening and she massaged and worked on opening his fingers very gently, speaking kindly to him while doing so. He seemed extremely excited in response to her presence, but she reports she feels he does not recognize her. He appeared to want to get out of bed as he seemed to be deliberately trying to swipe his covers off and edge to the side of the bed with extremely uncoordinated movements. In fact, we sought out nursing staff because I was worried he might fall out of bed, and because his mother and I did wish to have a visit and he also needed to be changed.

BT did not have a comprehensive functional assessment of all habilitative areas that accurately identified all of his strengths, needs, and preferences. He had the usual nursing facility assessments (MDS, daily nursing care needs, medical needs), but not the scope and type of assessments that are standard practice for people served in the IDD system of care who live in community settings. In the documents I reviewed, although he had a PASSR Level 1 screen that was positive for IDD, I did not find a PASRR Evaluation. I also did not find any assessments addressing sensorimotor development, affective development, independent living skills, communication needs or social development. He had Speech and Language Professional services assessment related to his swallowing problems, but not to assess and determine if anything further could be done to help him have as much functional communication as possible. He might be a candidate for an assistive technology of some kind, but this question was not assessed or even suggested to be a future area of assessment. BT has limited ability to communicate and this may be due in part from the degree or extent of his cognitive disability. However, it may also be that he has difficulty with the production of speech (a neuromotor symptom associated with CP). If he were provided with a communication device or book of pictures or small representative items in an array, he may be able to point towards pictures or items to communicate simple requests, even if he has a severe level of intellectual disability. This could dramatically enhance his level of independence.

BT has not received the necessary nursing facility and LIDDA specialized services, with the appropriate intensity, frequency, and duration, to address all need areas, though he has had some intermittent PASRR services. On February 11, 2016, BT was documented as receiving OT services. However, on September 8, 2016, BT's service coordinator's Quarterly SPT Meeting Notes state that BT's OT services would be discontinued because the Director of Rehabilitation at BT's nursing facility noted that he was able to grasp objects with his hands and therefore his OT would instead be replaced with restorative nursing care. The September 8, 2016 follow-up note stated that OT had been stopped in the summer and replaced with restoratives services because BT was able to grasp objects. Also at this meeting, it was stated that BT started PT on September 28, 2016. At that time, it was noted that BT was "currently working on positioning and ROM [Range of Motion] 3 times per week." At the February 11, 2016 Quarterly SPT meeting, BT's Director of Rehab also remarked that they would start habilitative PT for BT. A September 27, 2016 Person-Directed Plan for BT also notes under Occupational Therapy that "[BT] would like to gain strength in grasping objects."

BT also received PT and had a PT Plan of Care. A Physical Therapy Plan of Care dated July 5, 2017 states that "skilled PT is required to improve postural alignment in new WC in order to prevent skin breakdown, prevent further contracture, maintain joint integrity, and decrease risk of falls." I am unclear regarding how long this PT continued. There were not any actual OT or PT notes to review. There were service coordination notes referring to services such as one dated March 3, 2017, stating that PT was discontinued, and that OT was working on ROM. Another dated April 27, 2017, stated that "Rehab." reported that BT has OT and PT now and was doing well and that there was "no dc date in sight." Another service coordinator note dated May 12, 2017 states that the Rehabilitation staff at the nursing facility reported that BT will be picked up by PT in the near future, but had no services at that time because he "met all his goals." The records indicate that these services were not provided continuously. As previously noted, there was a discontinuation of OT in the summer of 2016, and at the time of my visit on August 21, 2017, there were references in the record that BT would be picked up for PT soon.

When I visited BT's nursing facility, BT's Physical Therapist reported he would be picked up for services soon. She was unaware of the differences between rehabilitative and habilitative services, but at least did understand it was possible for him to get continuous PT to maintain his current degree of any intentional or controlled movement, maintain his strength, and prevent worsening of contractures. She was very adamant that her professional opinion was that his smiles and responses and movements were involuntary. This is in contrast to observations of others close to him, as well as my own, that at least in some situations, he does seem to be trying to communicate or engage in a purposeful movement (however limited). For instance, as noted previously, when his mother and I came into his room, he seemed to be trying to move as if he wanted to be helped out of bed. A March 2, 2017 IDT meeting documented that BT's PT was recently discontinued, and will be picked up later. It was also reported that "he will eventually get back to the movies," but apparently this does not happen often, despite this being one of his favorite activities. An April 22, 2016 note stated that the SC visited with nursing facility staff to inquire whether the nursing facility could assist BT to participate in future movie outings since there was no ILST provider available that had a wheelchair accessible van. The nursing facility agreed to ensure that

BT has “a turn” to go to the movies. The June update after this meeting did not clearly address his specialized services. Despite his increasingly tightened hand/fingers (worsening contractures), BT was not given anything to place in his hand during the day to help prevent the contractures, though he wears a brace (on his right hand) at night per his LVN. The LVN who works with BT told me she thought he was maybe getting OT and PT, but saw these are separate from her work. If he was getting these services, it would be important for his entire care team (including his LVN) to know what services he is receiving so that they can support his goals and needs.

BT does have a CMWC. While at the nursing facility, it appears he has not had consistent PASRR ST, PT and OT services that are important for him to ensure that his contractures, strength and swallowing do not become more problematic and to at least maintain, to the greatest extent possible, his current level of capacity for movement to stem the progression of his contractures, maintain strength, provide oral stimulation programs, attempt use of visual aids or other means of improving any possible means of his communicating functionally with others.

At the time that I visited BT at his nursing facility on August 21, 2017, he was not receiving any LIDDA specialized services except for service coordination. A December 17, 2015 note addressed PASSR ILST. In a discussion with his mother, it was noted that this service could support his visiting her and going to a movie, and she “liked the idea.” The next note written by BT’s service coordinator made no reference to ILST. BT had been approved for ILST services through a contracted provider following his hospitalization. This was noted by SC in a progress note dated February 11, 2016. For his February 11, 2016 ISP SPT meeting, his mother/guardian had been hospitalized so the meeting was held without either BT or his mother/guardian present. At that time, it was noted that a contract for ILST had been signed and that the service should start soon. However, service coordination notes of June 30, 2016 and August 21, 2017 state that BT’s ILST services were discontinued because there were no service providers available to provide BT with ILST because they could not meet his needs. Additionally, BT’s records do not indicate that BT ever actually received ISLT services and BT could have also benefitted from day habilitation services however his LIDDA staff were not sure if they had a contract with a day habilitation program that would be able to serve BT.

Based on my review, I am concerned that BT may have suffered loss of strength and that at least the pace of the worsening of contractures and swallowing may have been prevented or slowed if he had more consistent specialized services of OT and ST. His mother described functional decline that is expected with CP, but also can be mitigated to some extent with aggressive service provision. I inquired about training for nursing staff just regarding the basics of working with people with IDD so that professionals and direct support staff would have some familiarity with conditions like CP and learn ways to better communicate with people who have functional communication deficits. Apparently, this is not anything done routinely.

It cannot be concluded that BT has been receiving active treatment. It is unclear how often he gets out into the community or to a movie theater. Despite the SPT endorsing his potential to benefit from ILST, he has not been provided with these services, because the agencies with which the LIDDA contracts to provide this LIDDA specialized service do not have a wheelchair-accessible van. BT has not been provided with consistent and aggressive OT, PT, or ST, services that would have been able to maintain and promote his independence. When we saw him, he had long fingernails and scratches on his skin from his inability to control contractures and movements. BT’s mother remains worried that he is in bed a great deal.

BT does not have a professionally-appropriate ISP that was developed based on a comprehensive, person-centered assessment that includes all needed services and supports to successfully transition to the community. The ISP and other assessments completed were not comprehensive; goals set for the ISP (Desired Outcomes) are not person-centered and there were not any means to measure progress towards goals that would address all of the areas noted above. Though some of BT's interests and preferences were noted, the ISP was not written in a way to promote his independence or help him prepare for a life in the community where he can enjoy more opportunities to engage in activities for which he has demonstrated interest. There was no documentation indicating any discussion regarding transitioning to the community, or identifying potential barriers to community living and how to address them. It was documented from an ISP that his Assistant Director of Nursing "admires that I am content and happy with where I am in my life." This is concerning because, since he cannot say these words, there might be some interpreting for him as to what he feels. It also might influence his family that what is being valued is being content where he is. This might inadvertently cause some pressure on a family member, such as BT's mother who desires avoiding any perceptions of judging nursing facility staff, people she must rely upon to care for her son.

BT's mother reported that she was very cautious about complaining even when she was concerned about BT's care. Generally, a person-centered ISP would more consistently identify a person's strengths (i.e., if a person seems to be able to take joy in just being around people, has a warm smile, etc.). It is concerning to identify a positive attribute for a person with IDD as being that they are accepting of the decisions made by others for where they will be. BT's mother (and guardian) was not present either in person or by phone at many of his SPT and ISP meetings. It was not clearly documented how it was then ensured that he had a "voice" in regards to planning his care."

I believe that BT would benefit from living in an integrated setting with appropriate community services and supports. He could be adequately and safely served in the community. His mother reported prior residential placements in which BT had negative experiences including a placement where the home was not clean and a second where he was allegedly given what she believed to be an overdose of medication to "quiet him down". He was hospitalized having had seizures that included generalized tonic-clonic seizures. BT was placed in the current facility following his hospitalization. His mother did not make this choice. I have personally seen individuals with the kind of challenges presented by BT residing successfully in community settings. If BT lived in an appropriate community placement with an appropriate ISP to address his individual programmatic and other needs, he would be able to have access to many more activities, participate in the community, and would not be spending long periods of time in bed. If BT has been living in a less restrictive setting, and had he received more consistent PT and OT to help prevent conditions like advancing contractures, he may suffered less loss of function. He would benefit from residing in a care setting where his nursing and other support staff commonly work with individuals with CP.

I do not believe that BT's mother, who is his LAR and guardian, made an informed decision for her son to remain in a nursing facility and be in a restrictive setting when a less restrictive option could have been made available. Unlike what is reflected in documentation, BT's mother readily agreed that she would be willing to learn about day habilitation services and other Specialized Services and about possibilities for future community living, despite the experiences that concerned her from a decade ago. It is important that LIDDA staff know the history of these kinds of experiences to help guardians and individuals make an informed choice. It did not seem that this history was understood or addressed by LIDDA staff. On BT's CLO form dated February 11, 2016, the Service Coordinator concluded that BT "is satisfied" with residing in the NF because he smiled when she asked him if he was. His mother seemed to understand that things have changed in systems of care in the past decade, and there could be possible opportunities for her son that might improve his quality of life. She did not express any hesitance and did not protest or convey that she wanted him to stay in the NF, or that she would not consider CLOs or a day habilitation program. On the contrary, she expressed regret that her health was declining and that she was not visiting him as often as previously. This was surprising because it seemed clear that LIDDA staff did not appear to have much knowledge of BT's past experiences, the experiences of his family, or how to assist the family (guardian). Knowing the past negative experiences caused anxiety about any potential future move, I would hope to see documentation of efforts to help the guardian understand possibilities, provide reassurances to the guardian, and truly show options, but I did not find any documentation of this occurring. BT's mother expressed concern that visiting and advocating for her son's care at the NF was important and her belief that without more of her presence, he might not get optimal or even basic care at times (i.e., that he might have times where he is incontinent and not changed and cleaned up in a timely manner). She expressed a wish that he could have more opportunities and supports. She expressed concern that her values and beliefs, that include her wish that her son be clean-shaven, are not always respected. At the same time, she expressed gratitude that he has care and conveyed that she regretted that she herself cannot take care of his complex needs. She described how he used to love to eat Fritos, but as his condition deteriorated, he was placed on a pureed diet.

I was not able to speak with the Service Coordinator who had been working with BT in recent months and thus unable to clarify the history of conversations with BT's mother with regards to efforts to identify any concerns about looking at community options, or interests in LIDDA based community service options or regarding nursing facility PASRR services. I asked the LIDDA Program Manager (who would have supervised the SC) how he would teach a Service Coordinator to do this, as a supervisor, and then how he might approach a parent who had past negative experiences, but ones that were very old (such as in BT's case). He did list the steps that are required in presenting a CLO to a family, but did not elaborate on how he would specifically work to allay the parent's fears or provide more concrete information regarding how her son's life might be different if he were placed in a well-planned and appropriate community placement with ISP-identified supports in place to meet his individualized needs. The Program Manager was unaware that BT's mother was open to learning more about BT's placement options. Continued institutionalization in a nursing facility is neither necessary nor appropriate for BT.

CB

Date of Visit: August 22, 2017

I spoke in person with CB, his service coordinator and his nurse at the facility, his uncle by phone, and reviewed the records made available to me.

CB is a 36-year-old man who is a double amputee, who relies on a wheel chair for his mobility. He has numerous other diagnoses and problems listed in records in addition to the amputations including: schizophrenia, mood disorder, pseudo bulbar palsy, seizures, legally blind, hallucinations, delusions, history of aggression, behavioral outbursts, dementia, memory problems, and disorientation. He was admitted to a nursing facility on 05/17/15 from a psychiatric hospital and it seems he may have transferred from another part of the facility about one year ago. There apparently has been a lot of turnover at the facility recently which is under new ownership, so that other professionals also would have had minimal historical knowledge of CB. There was no other information regarding CB and his past in his records, but I was able to learn a few things from a phone conversation with his uncle after my visit (see below). He was identified as PASRR positive on 3-25-16. He is treated with a long list of medications, including antipsychotic drugs.

CB does not have a Legally Authorized Representative or guardian. No one involved in his care seemed to know and understand his history. His uncle, who is his only involved family, recounted how CB had problems in school as a youth, and that he used drugs and was oppositional to his mother's care, ending up homeless and living on the streets around the ages of 14 to 16 years. CB lived in a facility in Detroit, and his uncle brought him to Texas after his mother died. CB's uncle also reported that CB lost his limbs to gangrene. CB's uncle recalled CB having been in a total of about four different facilities, and noted that the current one was the best of these. When I talked with CB, he spoke in an unusual low monotone, with an atypical cadence often repeating certain phrases. He said things like "I can't see a thing." When asked what he does all day, he said he was "chillin' like a villain" and he smiled. He is known for his passionate love of potato chips (and he has particular tastes and wants specific kinds).

When I talked with CB, there were times that he could answer questions in a way that seemed he was truly understanding them and telling me what he wanted or what he thought. For example, I asked him "[w]ould you rather stay in your room or be out with the people?" He responded "out with the people." At other times during our conversation, CB seemed not to understand the question or to be distracted or confused such as when I asked him what season is it now. He hesitated and eventually answered "winter." "I don't go outside in the winter," he added. This visit occurred in August. CB has quite a bit of language, but rarely answered in full sentences, though he could at times. This may have been because he did not know me. The inconsistencies in his responses added to my concern that he might not be able to make informed choices about services, especially if a great deal of work was not done to actually have him go to visit available settings, rather than just talk about them.

CB did not have a comprehensive functional assessment of all habilitative areas that accurately identified all of his strengths and needs. He had the usual nursing facility assessments (MDS, daily nursing care needs, medical needs), but not the scope and type of assessments that are standard practice for people with intellectual and/or developmental disabilities, nor did he appear to have assessments specific to his particular needs. The MDS forms, for example, are comprised of computer generated lists of items checked off, without any personalized descriptions about CB. His PASRR Evaluations recommend only service coordination, though one identifies a number of areas in which he needs assistance. I did not find any assessments addressing sensorimotor development, independent living skills, cognitive assessment or how his visual impairment should be treated and approached, although his vision was assessed. There were no assessments of his behavioral challenges, independent living skills, or social development needs (he has some issues in terms of his interactions with others, but wants to be around others). These are all assessments that would be warranted by his particular needs and important to ensure he is receiving appropriate services and supports. There were some very basic reviews of his ability to transfer himself. There was an assessment by a Physical Therapist when seeking a CMWC. Because of CB's sight impairment, he needs some assistance to get around. CB's nurse told us that he can get out of his room and down to areas where he wants to be around other people, but he cannot get back to his room without help. Given his vision impairment, all efforts to promote his independence need to be informed by an assessment of this area. His ISP did not contain any descriptions of what barriers there were to his living in the community or how these might be addressed, or what an appropriate set of services and placement would look like for him.

CB is not receiving all necessary LIDDA and nursing facility specialized services with the appropriate intensity, frequency, and duration, to address all need areas. With respect to nursing facility specialized services, he has had minimal OT services (which may be because he initially refused services last year, according to his service coordinator). In his 7-26-17 ISP, one of his statements was that he is blind and "I need to have more information when discussing services, to be able to understand what is being discussed," a statement with which I would agree. He did not seem to be receiving additional support to understand what services he was refusing, something regarding which a vision specialist might provide help. A vision specialist may work with individuals and their support staff to develop individualized strategies that increase a person's safety and independence. His OT documented efforts to provide CB with services, she stated that he "just keeps asking for potato chips." At the ISP meeting, it was noted that CB had refused his OT services. Based on this, it was suggested the SPT should "reduce this service out of his plan," rather than finding a way to help CB get the needed services. At this meeting, after his service coordinator broached the topic of OT services with him again, CB said that he would not refuse the OT services if they were offered again. CB wanted the OT help for his ADLs and bathroom support. As a result of this meeting, OT was finally planned as a PASRR service. The Service Coordinator requested a nursing care plan and documented that the facility would complete a care plan that day. A request for authorization for specialized OT services was finally submitted on August 3, 2017. Up until that time the OT that CB had received appeared to have been based on a time-limited rehabilitative service, rather than a habilitative service to help him maintain and develop needed skills.

With respect to LIDDA specialized services, he could, but does not attend a day program and could benefit from attending one or possibly, having vocational training. ILST services could also help him prepare for a community setting. CB expressed in his ISP that "I want to do as much as I can for myself," but the response of the team was a recommendation to have the occupational therapist address the problem that he dumps out his urinal on the floor. CB apparently also has an issue of crawling into others' rooms and this is naturally seen as a behavior problem, and may even be seen as part of his mental health challenges. Though he demonstrated no clear signs of psychiatric disorder when we spoke, he is treated with many psychoactive and anti-epilepsy drugs (at least as of is 7-26-17 ISP document). It may be that I did not happen to see any of these symptoms in my brief visit. However, it is quite common for individuals like CB to be medicated to manage behavior rather than receiving other needed services, such as having a functional behavior assessment and a Positive Behavior Support Plan, and having an engaging and structured day of activities. CB's uncle also told us that CB had refused to have any prostheses. Behavioral treatment might assist CB to be motivated to at least try this out (as well as helping him give other needed services a try, ones that would help him reach his own stated goals).

I believe CB would be more likely to be engaged in services he needs, such as OT services that he refused, to maintain and improve his independence, if he had a positive behavior support plan. A behavior plan could help guide the OT and others regarding how to approach and motivate CB to engage in the services he states he wants and that he needs. These plans can be crucial to helping people like CB. He does not have ILST or attend a day habilitation program, despite enjoying his community outings, enjoying music and singing, and being around people. He reportedly declined these services. At the same time, everyone agrees it is very difficult to know what he understands about services offered to him.

CB is not receiving active treatment that could promote his independence, maintain skills he has now (such as transferring on his own), or to promote overall functioning with as much self-determination as possible. As stated above, he has not received a comprehensive functional assessment or set of assessments that would identify his needs in a variety of necessary areas and he has not been receiving all needed specialized services. Those services he has received were minimal and intermittent. Instead, it seems that CB receives almost no assistance at all to promote his independence and overall functioning. His uncle stated that whenever he visits, CB is in bed. When I visited, CB was in bed.
On an activities services note dated 8-17-16, it was documented that he "loves to take naps." In the month of August 2016, weekly notes included a time where he was taken out for coffee and doughnuts. There are no data summaries reflecting his rate of attendance at activities but his records state that he needs help to go out to do activities in the community and will leave when he wants to. CB's nurse, who knows him well, noted that CB sleeps a lot during the day and is engaged in almost no nursing facility

activities. I asked him about things he might like to do and he agreed he likes going for rides, going to church, and that he likes barbecues. I asked if he would like help to go out more often to which he responded “yes.” I believe if I had asked him if he wanted ILST he might have said no, for two reasons. He may say no to people he does not trust or have rapport with when they are asking him things and secondly, he may not have understood what he was refusing. With someone like CB, it is important to gain trust and ask questions in a very concrete and clear manner, using language he can understand.

CB does not have a professionally-appropriate ISP that was developed based on a comprehensive, person-centered assessment that includes all needed services and supports to successfully transition to the community because, as noted, CB’s ISP-related assessments and the developed plan are not comprehensive. CB was not provided with individualized transition planning and there is no record that anyone considered what services he would need to transition to the community as the section in the ISP that would include a transition plan was not filled out. There were insufficient assessments completed to inform the development of a plan to address his strengths, weaknesses, needs and related goals. There is also no clear means by which to measure CB’s progress towards the limited goals that do exist in his ISP (i.e. no target dates or expected rates of demonstration of new skills or similar types of strategies so that progress can be measured objectively). Additionally, the ISP does not contain person-centered goals. For example, on page 8 of CB’s most recent ISP, the outcome statements included, “I will use the bathroom better,” and “I will do activities.” These are not person centered goals and there are no explanations of how progress towards these outcomes would be measured to determine that CB is benefitting from his plan and does not need any modifications to improve outcomes. Based on what I learned about CB, I believe his team could easily have developed more person-centered goals and have had an appropriate ISP developed for him, even though they seemed to have had no historical perspective on CB. The plan that was developed and monitored by the service coordinator is overly simple and there are no target dates or data targets to assess progress, as noted. For example, given a goal for CB to “do activities” with staff support, it might be stated that a goal was for him to be attending a minimum of 4 activities daily, 6 days out of 7 weekly, by the next quarterly review.

Another example of the failure to provide CB with a person-centered plan, is the failure to address the concerns of CB’s uncle that CB has gained a lot of weight (CB used to weigh about 135 lbs. and now weighs over 200 lbs.). His uncle conveyed to me that he worries this will eventually further reduce his independence. Dietary notes described him as being on a regular diet, however, CB’s uncle attributes the large weight gain in part to certain medications he takes for psychiatric reasons. He has advocated for consideration of medication changes, but these have not occurred. If CB continues to gain weight it has the potential to impact his ability to transfer and his overall mobility. This will impact his ability to be independent. Despite these concerns, this issue was not addressed with an outcome statement or goal in his plan.

I believe that CB would benefit from living in an integrated setting with appropriate community services and supports. It was noted in his 7-26-17 ISP document that CB does not have any routine skilled nursing needs. He could be adequately and safely served in the community. He is young and most of the people he resides with are elderly and the activities in nursing facilities are often geared towards the majority population served. His nurse did not think he had made any friends and he might be able to do this if he lived with people nearer his own age and who might have similar interests for activities. His SC felt he would benefit from moving to a community setting. Continued institutionalization in a nursing facility is neither necessary, nor appropriate for CB. I believe he has suffered harm because he did not get all the assessments and services he needed.

I do not believe that CB has made an informed decision to remain at the Nursing Facility. The SPT and service coordinator gave CB documents about CLO and verbally described options to him. There was no documentation in his most recent ISP (7-26 -17) of a discussion of CB's perceived barriers to community living CB's CLO from 5-11-17 had minimal discussion of the barriers to community living as well. The service coordinator reported that he asked to stay at the facility, and she told him "of course" he could stay. She adds that he says he is very happy at the facility. She stated that he understood that he could live "somewhere" else, but that really, she was "unsure of his actual comprehension." She admitted she also did not think he really understood any of the options for specialized services or community placement. She does not know his history as noted, even though an interview with his uncle enabled me to learn some important facts about his background, which could help the SC to better address his past experiences and challenges. This service coordinator did appear to appreciate the benefits of community living, but seemed to believe that she could not promote community living over the nursing facility. She explained the tension between helping a person understand their options and being overly directive when it is hard to know what someone understands. The pages in the ISP where a detailed description of what an appropriate community living option would be for CB are left blank. If these things were outlined, it could support communication with CB about what it would really mean to live in a community setting, and assist in planning services to help him develop or maintain skills he needs to live in his community. Similarly, a meaningful visit to a community-based setting may help him to understand his options. I asked him if he would like living somewhere where he could maybe go out to eat more, be outside doing things and maybe even live somewhere closer to his uncle, and he said yes. Given the description of his having minimal skilled nursing needs, it is hard to understand why there has not been much more effort to help CB experience aspects of community life to help him understand better what he is opting out of. He has not had any visits to community settings or even to a day habilitation program to see if he might like these settings when he really gets to experience them. His 3-30-17 physician assistant medical review note reported that he "remains confused at baseline" and his Minimum Data Set screen states that his cognitive skills are "severely impaired-never/rarely made decisions" and that he has both short and long-term memory problems. I seriously doubt he can conceptualize what it means to live "somewhere else," especially based only on abstract discussions twice a year. If his caregivers and SPT feel he has memory challenges and dementia and is disoriented, then there should be someone trying to get him an LAR or advocate to assist him to make an informed choice.

DD

Date of Visit: September 7, 2017

I met with DD, his favorite nurse, social services director, service coordinator, LIDDA IDD Director, MDS coordinator, the Rehabilitation Director and his mother, and I reviewed available records.

DD is a 25-year-old young man who has a very debilitating case of Multiple Sclerosis (MS). He came to be in the nursing facility after having been homeless, then living in several unsuccessful group homes. DD's story is especially heartbreaking, as he may not have had the terrible decline he experienced, had he received effective medical care earlier in the course of his illness. DD was diagnosed with MS as a teenager. He was not entirely compliant with his early MS treatments. He graduated high school and moved on to college, but left school as his illness worsened. According to his mother, as his condition progressed, he began to abuse drugs and he lost motor skills. He also experienced a cognitive decline and neuropsychiatric sequelae from the MS. For a time, he was homeless, which was followed by a series of group home placements. During this time, according to his mother, he experienced multiple psychiatric hospitalizations in addition to many emergency medical events related to his degenerative neurological disorder, and nearly died on multiple occasions. DD's mother described his very negative experiences in these group homes, including one where staff allegedly stole his possessions and another where a provider dropped him off at the Police Station because of his behavior. On one occasion, she found him neglected and near-death and had to get him to the hospital herself where it was determined that he had aspirated. His mother explained that DD's case of MS is particularly severe because of his initially poor medical care, DD's own noncompliance with the treatment, and because he has a severe subtype of MS. DD is not ambulatory, requires a customized motorized wheelchair, a shower chair, and a two-person lift for transfer. His height at 6'4" adds to the challenges of assisting him in and out of his chair. He has difficulty swallowing and speaking. He needs care due to incontinence and has very severe tremors that are worse when he is up in his wheelchair. All of these symptoms have emerged or worsened over the past 2 years.

Before his deterioration, DD loved playing basketball. He is still vibrant and funny, loves movies with Denzel Washington in them, listening to rap and R&B, and has a great sense of humor. His MS is so bad now that he can barely articulate words. He must be fed and is on a liquid diet. He uses a wheelchair and experiences severe tremors. He sleeps most of the time and has little energy. His mother visits every day and feeds him dinner. He came to the current nursing facility from a group home in December 2016. His sister volunteers as an activities assistant at the nursing facility on weekends. DD's aunt and uncle visit him. In 2015, his ISP noted how if it were "in the realm of possibility," he would have loved to have a trip to Atlanta where so many of the musicians he admires might be seen.

Based on my review, DD has not had a comprehensive functional assessment of all habilitative areas that accurately identifies all of his strengths and needs. DD's PASRR "Eligibility" Form dated December 29, 2016 documented that DD required Occupational Therapy, Physical Therapy, Speech Services, DME, a Customized Manual Wheel Chair, and Independent Living Skills Training, but there is no PASRR Evaluation form in the records. His January 25, 2017 IDT also recommends all of these services but not ILST. DD received an assessment for PT on December 28, 2016. He finally received some of the other assessments he needed after weeks of waiting for correction of a paperwork problem related to his Medicaid eligibility. He received an OT assessment around February 24, 2017 and again on June 24, 2017, and a Speech Services assessment initially related to his dysphagia on April 22, 2017, and again on May 4, 2017. But no actual treatments or therapies occurred initially (see below regarding periods when some services were provided). His mother reported that he also received little to no services when he was in group homes, and that he deteriorated rapidly during this time as well. In two short years, DD's condition deteriorated significantly. He did not have an assessment to examine his needs with regards to potentially having ILST. He did not have an initial assessment regarding his challenges in the area of communication, though he may have been more articulate at this time.

DD has not been receiving necessary nursing facility and LIDDA specialized services, with the appropriate intensity, frequency, and duration, to address all need areas. These services may have at least slowed the progression of his illness and helped him to have more community based experiences with people his own age. DD did not receive the services identified as needed in his December 29, 2016 PASRR Evaluation beyond an assessment initially. These services should have been designed to promote acquisition of the behaviors necessary for DD to function with as much self-determination and independence as possible. In DD's case, these services were also critical to slow the progression of his MS to the greatest extent possible. In DD's May 25, 2017 nursing facility quarterly assessment, it was noted that "PT and OT have finally been given the OK" but that Medicaid has been "messed up or pending since January." In a service coordination note dated February 23, 2017, the Service Coordinator documented that there had been a complaint submitted that the IDT had suggested PT, OT, ST, a customized manual wheelchair, and an air mattress as specialized services, but the nursing facility did not provide them. The note documented a discussion by the nursing facility staff regarding how this was "not their fault" and now they were “in trouble” because DD did not have the appropriate Medicaid due to his paperwork. A note from DD’s June 22, 2017 service planning team meeting indicates “[M]edicaid was messed up it is now approved and all items in the works. CMWC IN and he looks good in it.” Ultimately, it appears DD did not receive the critical services he needed for years in the community as well as for months in the current nursing facility. DD’s Service Coordinator understood the need for habilitative services, but said she did not feel she could tell the nursing facility staff what DD needed. In other words, as a Qualified Intellectual Disabilities Professional and PASRR Service Coordinator, she felt he needed to be receiving more nursing facility PASRR services. The nursing facility’s MDS coordinator stated that she was aware that people “come off services” even when it would be appropriate for them to remain in the services to receive preventive, habilitative care.

There was a request for PASRR OT dated 2-24-17. ST, OT and PT were all approved through PASRR 3-7-17. After an assessment, OT was documented as having been recommended and may have been provided between 2-24-17 and 4-24-17. This was documented as being initiated due to a decline in function and was funded through Medicaid. Speech and Language services were provided (an evaluation was done) and documented with a date of 5-4-2017 due to decline in his swallowing ability. Previously, there was an assessment and speech services are documented as recommended and may have been provided for the period between 2-22-17 and 4-13-17 but then discontinued. There was a plan at this time to seek a communication device that he had not yet received as of my visit. A second PASRR authorization request for these services was dated 6-24-17. Attached to this was an assessment for an approximately one month long certification period (6-24-17 to 7-21-17). I could not find the documentation to verify that the service was provided.

DD’s CMWC was first requested on December 27, 2016. This was denied on March 20, 2017 and the request was submitted again on March 27, 2017. As noted above, DD did not appear to receive the CMWC until June 2017. A specialized mattress was requested on March 29, 2017. A DME assessment and specialized mattress were PASRR authorized almost two months later, with a date of 5-17-17. Another document reported that the quote for the mattress and pump (DME items) was obtained 2-27-17. Though not a specialized service, it is of note that DD was unable to receive dental care at the facility due to insurance constraints (having NF Medicaid), unless his mother privately paid, and he would have had access if he lived in the community. Based on available documentation, it appears that DD at best received delayed and intermittent PASRR NF services that were potentially ones that could slow the progression of his functional decline.

With respect to LIDDA specialized services, it does not appear that DD received any of these, although he would have benefitted from day habilitation and ILST in order to maintain skills and engage more with his community. His PASRR Eligibility form recommended ILST, and a July 2015 assessment recommends day habilitation, but as of his May 27, 2017 SPT meeting he was not receiving any LIDDA specialized services. Based on my interviews with family and professionals, he clearly would have enjoyed having more opportunities to be out in his community.

DD has not been receiving active treatment, including services directed toward the acquisition of skills necessary for him to function with as much self-determination and independence as possible. Such treatment should be aimed at skills building, but also is supposed to help the person to maintain skills and functioning and to prevent further regression to the greatest extent possible. At the current nursing facility, DD did not receive these critical services for months despite needing them, because of an administrative error. His MS has progressed extremely quickly. The progression might have been slowed had DD received continuous, aggressive treatment aimed at maintaining his functioning. Yet a February

22, 2017 note from DD's Service Coordinator stated that DD "is thriving in this environment with the attention and social interaction he is being provided," and that they "spoil" him. However, based on his mother's report, I do not believe that DD is thriving. In fact, in the last two years he has declined significantly: he lost the ability to walk, to transfer, to speak, and to swallow. The Service Coordinator's comment that he was "spoiled" reflects a lack of understanding of the need for aggressive services to provide DD with the best quality of life possible.

DD does not have a professionally-appropriate Individual Service Plan that was developed based upon a comprehensive, person-centered assessment and that includes all needed services and supports for DD to successfully transition to the community. DD's July 15, 2015 ISP noted that he wanted to live in a small group home in his old neighborhood where grew up. It also noted that he wanted a girlfriend, liked living with people his own age, and that he liked peanut butter and jelly sandwiches. In his May and June 2017 ISP documents, the descriptions of what is important to this young man consisted of only 20 words, and did not include a mention of his family, reflecting a severe lack of understanding. Most of the ISP is like this; there are very brief phrases or one to two word descriptions of his functioning and needs. The service coordinator notes, when checking on his progress, never identify data tracked to be able to carefully monitor his progress. DD does not have person-centered, measureable goals that are aimed at supporting his maximum independence. For DD, this was noted as follows:

> *Desired Outcome 1: "[DD] would like to be able to continue to live here [at] hacienda. [H]e has had to move so much and [been] kicked out of multiple places. [H]e is very happy right[] now and wants to stay that way." Evidence of progress: "[DD] will continue to live in Hacienda."*

These are not person-centered goals that reflect what he and his mother wanted, such as community outings and involvement, and that he maintain as much of his ability to move and communicate as possible. In his most recent June 22, 2017 ISP, page 9, the "Transition Plan to the Community" section, was left blank and therefore does not reflect an assessment of his strengths, preferences, and needs regarding transitioning to or living in the community. This is unfortunate because in order to address DD's specific barriers to community living, it is important to describe what an effective, safe placement would look like. DD's needs could be met in a community setting. Unfortunately, DD's 2017 CLO does not address whether DD could live in a community setting other than to say he cannot because of his illness, and that community residential settings cannot meet the type of care needs he has. DD's service coordinator did not elaborate on why she believed that to be the case.

I believe DD would have benefited from living in in an integrated setting with appropriate community services and supports. DD's needs could be met in a community setting where the staff has appropriate training and supervision, where some nursing care was available, where he could access other rehabilitation services and where he could have access to areas in his wheelchair, transportation, and day program services. I have personally worked with people who had such needs and been served in community settings. His service coordinator documented that he is happy and that he smiles and jokes and is "stable" at the nursing facility. However, I believe he could have a much richer life in the appropriate community setting. The improvement in his mood at this facility is in contrast to nearly dying in group home placements, based on the report of his mother, who now fears change could cause her son's death. But his current placement does not reflect the best and most integrated setting, and his social worker agreed that DD lacks "quality of life here," and wishes there were more opportunities for him. She added that "the activities here are geared to old people." DD's favorite nurse echoed this sentiment, stating that it was sad that he is with primarily old people. The LIDDA staff also stated that if an appropriate placement existed, then DD could benefit from living in the community.

Unfortunately, there are significant barriers to DD's community placement. First, his Service Coordinator stated that there were not any community residences close by that had the necessary services and could meet his needs. DD's mother visits him daily and would not be able to if he moved to another community. His Service Coordinator also stated that it could take years to find a community residence with the features needed to serve DD safely and appropriately but agreed that there are such placements. The nursing facility Rehabilitation Department Director said the providers do not have the funding to meet his medical needs, but if they did, it would be much better for him. The second barrier is that DD's mother is reluctant to place him in the community given their terrible experiences in community settings that resulted in acute hospitalizations, a physical assault, and severe weight loss. DD's ISP should not be documenting what his assessments, goals and needs are based on what happens to be available locally, but should be documenting what he really needs.

I do not believe that DD or his mother are making a fully informed decision for him to reside at the nursing facility since his understanding of options is likely compromised and not easily assessed, and his mother firmly believes there is no reasonable placement that could safely care for him. His mother repeatedly stated that community care group homes and foster care style arrangements are for "people who can do most things for themselves" and that these providers do not want to do the level of work required to care for someone like her son. She had reported she wanted to have him at home but has to work full-time. She reported asking for help to care for DD at home, but noted that she was told that she could only get assistance during the day and would not have any other supports, such as on weekends and evenings or respite so that she could manage a life caring for him at home and be able to keep her job. Further, DD's ISP states that "HCS group homes cannot provide him competent needed medical management, oversight and care."

On his January 17, 2017 and May 25, 2017 CLO forms it is simply stated that he wants to stay in the nursing facility, that his mother wants him to stay, and that his MS is a barrier to community living. This stands in contrast to documentation and his mother's reports which suggest that, as discussed above, the main barriers to his living in the community over recent years has been the lack of appropriate care provided in community settings leading his mother to believe that no community setting could ever manage a person with needs like those of her son. I found no documentation that any steps have been taken or planned to address these barriers. His mother's preference for the current setting, as she explained to us, is also based on her experiences that were very negative with past placements, in which her son almost died. In July 2015, DD's ISP clearly stated DD did not want to live in a nursing facility, but this was followed by a series of bad experiences in the community, and he ended up in the present nursing facility. She is not very happy about the current setting and clearly stated she would not criticize the facility due to her fear that would result in compromised care to her son. She reported seeing the current placement as the best of bad options available to her son. DD's mother comes every day because she believes that her presence is required to insure he is not neglected or is not receiving poor care. It is extremely difficult to know whether or not DD's mother would make the same choice if she had been shown possible placements that were safe and capable of meeting her son's needs, and that would provide him with a happier and richer life within his community. DD is not able to make an informed choice presently due to his emerging cognitive challenges without additional individualized information and support in decision-making.

JP

Date of Visit: August 23, 2017

I spoke with JP, his Service Coordinator, his nursing facility Social Worker, one of his nurses, a rehabilitation director, and his sister, and reviewed available records.

JP is a 73 year-old man who has a Mild ID. He has been diagnosed with epilepsy, unspecified dementia, peripheral vascular disease, delusion, anxiety, depressive episodes, hypertension, diabetes, and hearing and visual impairments. He does not have a guardian but is quite close with his sister who advocates for him. He lived with his mother for most of his life, and then with his sister and her husband. When his sister became unable to care for JP due to her own health concerns, he was placed in a nursing facility. He lived in four different nursing facilities and a group home (for 24 hours) before moving to his current nursing facility in June 2016. She stated that the current placement is better than the previous ones. He nearly died in the last facility related to drug errors. JP still wants to move "home" with his sister but she cannot manage his care safely any longer. His one group home placement was for only 24 hours. He was apparently placed with some other men who were much more severely impaired than he and he called her asking to come home, stating he did not like the home. JP's sister said the home was clean, the people were nice but she was not surprised and predicted in fact that he would refuse to stay. However, it seems he could have a different response to a placement more individually designed (as it should be) to provide for his unique interests, preferences and needs.

When I met with JP he was in his room, which was a small, double room that had minimal décor (no pictures, no personal items were visible.) JP grew up working on a farm. He was very proud of this. He apparently really likes animals and country music. He used to attend church and would like to return to church, but does not have transportation to it. JP can communicate well. He was teary during our visit, stating "if I get out of here it'll be okay".

I do not believe that JP was provided with a comprehensive functional assessment of all of the habilitative areas that accurately identified all of his strengths and needs. He had some assessments completed, but these were not detailed enough to address his potential needs. He had no behavioral assessment, yet he needs help to be motivated to come out of his room. JP had at least two PASRR Level 1 screens and at least two PASRR Evaluations (PEs). One PE, dated 5/12/2016 confirmed that JP was diagnosed with a mental illness, an intellectual disability and developmental disability. In this PE, the evaluator determined that JP needed assistance with nutrition, activities of daily living (ADLs), social and recreational skills, and independent living skills. Despite identifying these support needs, the only specialized services recommended on the PE was service coordination. In his most current PE dated 7/11/2017, the evaluator found that JP needed assistance with nutrition, ADLs, and recommended that JP receive specialized services including OT, service coordination, and alternate placement services. There was not any documentation of an assessment of his social needs, yet he is often isolated and sad. An assessment to fully define what JP does and does not understand (his cognitive abilities) was not done yet he is diagnosed with dementia. Turnover has been significant at JP's nursing facility, reportedly due to the family owned business being sold recently. His nurse thought JP may have had some cognitive decline, though others did not seem to see this. His sister has been worried about him recently. He has had OT and PT evaluations but without a focus on longer term goals. In the ISP, where there should be details regarding barriers to living in the community and how these might be addressed, no details are provided. The kind of community based care that would be appropriate for him is also not described.

JP is not receiving necessary nursing facility and LIDDA specialized services, despite the fact that there are many from which he could benefit. Documentation from his June 28, 2016 meeting for his annual ISP/IDT plan indicated he briefly received specialized services of OT and PT three times a week to strengthen his weak left side, and to address his poor balance. He was discharged from PT on 8-14-16 and OT on 5-26-16. It was unclear why these services were deemed to be no longer potentially helpful for him, especially given his documented needs. In terms of needs, it was noted that he needed help to remain mentally alert and interactive, and that he required help to ensure that he would not lose physical strength or skills and to maintain his ADLs skills, community living, independent living skills, and mobility and strength. It was also noted that he was gradually gaining large amounts of weight that threatened his mobility and independence (a fact that has worried his sister). By 11-30-16 he weighed 320 lbs. Despite concerns regarding loss of strength and mobility, JP does not receive habilitative OT and PT, both of which would benefit him. It was further noted that he had diagnoses in his records of dementia, psychosis, anxiety and depression, and that he wanted to spend more time with his family. JP seemed depressed when I met with him. Despite his psychological issues, no behavior therapy or support was provided to him. I believe he would benefit from PASRR behavioral services that could provide guidelines to his staff to promote his coming out of his room more. An ISP goal from 11-16-16 was "For me to spend time by myself" when clearly, this has been a sad and not very healthy behavior for him. His service coordinator was unaware that JP has behavioral health needs yet he has very clear depression, and several mental health diagnoses in his Nursing facility records. Furthermore, despite the fact he clearly wants to spend more time with his family, he does not receive any services like ILST that could promote and facilitate visits with his family. Despite the fact that JP was identified as having many needs, nothing was put in place to address them through the use of PASRR services either through the nursing facility or the LIDDA. Instead, it was documented that he does not need any more specialized services and that he is doing great, though there were no clear rationales documented to support these conclusions. In the most recent IDT meeting dated 7/28/2017, it was documented that the IDT found that JP needed specialized services but then only recommended service coordination.

The NF Director of Social Services mentioned that recently, there has been increased attention to PASRR and said something to the effect that, "…now that you guys are coming in they are finally serious about PASRR." JP's Service Coordinator explained that she relied upon the NF's Rehabilitation Department people to determine what specialized skills are required. She reported that she had not previously considered PASRR specialized services such as OT, PT, or ILST as being potentially beneficial in maintaining JP's abilities or in increasing his abilities and potential independence in the community (i.e. if he enjoys animals, she herself said, maybe he would enjoy going to a zoo). The SC seemed enthusiastic about exploring these services after speaking about them with me. The new Rehabilitation Services Director stated she had not been involved in JP's meetings and had not given an opinion one way or another regarding his potential to benefit from PASRR services. She further commented that the process for PASRR as being something they would look into only after exhausting Medicare Part A and Part B. She noted there are "a lot of hoops to jump through." She also was not aware of trainings about working specifically with people with IDD. She felt that if he was agreeable "it wouldn't hurt to have PT for" JP.

JP is not receiving active treatment, as evidenced by numerous statements he made and made by his family and his team. There is virtually nothing being done to ensure JP maintains his skills and to promote as much self-determination as possible. As noted above, despite clear needs for specialized services, he is not receiving any. He told me he would like to go to church and shared that it "ain't no fun around here" and that he spends "all day long in bed." He also stated that "If I get out of here I'll be OK," but he agreed it is important to find "the right place" (one that would meet his needs and be safe). I asked him if he would like to be able to go to see a farm or see some animals and he said "yes." I asked if anyone takes him out from the nursing facility to do things and he very emphatically stated "no." He said he had been in four different nursing homes. He said of all of them, this was the best. I asked him what he liked about being there then, and he again was very clear that he did *not* like being there or in any nursing facility, just that this one was better than the others. I asked if he would like living somewhere where he might get out more, maybe go out to eat, to live in a house again, maybe with just a couple of roommates (since he had indicated to me he preferred fewer people and not a lot of people). He said yes to this also. When discussing living in the facility, he began to cry. When discussing how everyone including JP talked about him spending most of his time in his room (and in bed), his social worker stated that JP likes to watch TV in his room. However, JP does not have a TV in his room.

JP does not have a person-centered ISP (which should have been developed based on a comprehensive review of all of his service needs). For example, from 6-28-16, he had outcomes and goals listed as "Outcome to get seizure controlled," "I want to maintain regular contact with family," and "I will have good oral hygiene." These goals are by no means comprehensive or person- centered apart from his wanting to see family. He was also being described as spending most of his time in his room. His ISP did not describe how to remove barriers to assist JP in living in the least restrictive setting possible. This did not seem to be a high priority expressed by his team members. It was unclear that anyone attempted to design or provide services and supports to successfully transition him to the community. Like many other people I met, he did not seem to understand what was really available to him.

I believe JP could benefit from living in an integrated setting with appropriate community services and supports. He could be adequately and safely served in the community. He did not have any problems that I have not seen addressed in community settings. His Service Coordinator also agreed that he could be served in a community setting. JP reported to me a significant degree of unhappiness regarding living in the nursing facility. He had negative experiences and even frightening ones previously, and is only settling for staying where he is now because of fears about the alternatives.

I do not believe JP made an informed decision to remain in the nursing facility. It was unclear whether he or his sister fully understood what might be possible for JP, despite the CLO forms having boxes checked indicating that materials were shared. There were some discrepant notes regarding his understanding of options. For example, in the CLO dated June 2, 2017, the Service Coordinator checked all of the four items indicating that materials to be provided were shared, and it was noted that JP understood his options, that options were given, that he does not want to leave the nursing facility, and that his family does not want CLO for him. By contrast, in documentation from just a short time later on June 28, 2017, it was noted that JP's "level of awareness is minimal." His service coordinator also said to me "I honestly don't think he knows the difference" when services and options were described to him. She shared that it may be that he and his sister do not want to "rock the boat" because the current setting is at least better than past ones. She did not believe that JP understood that it would be a higher quality of life to reside in a community setting and be out and about in his community. She speculated, "This is the best of a lot of bad options…. might be how his sister feels." The service coordinator admitted the previous bad experiences were a barrier in addressing community living, but acknowledged that she had not received any training regarding how one might work with a family with past bad experiences in community services. It is my impression that JP and his sister did not really understand what could be possible and were anxious about exploring options because of bad experiences in the past. Based on all of the above, in my opinion, continued institutionalization in a nursing facility is not necessary or appropriate for JP.

JM

Date of Visit: August 24, 2017

I interviewed JM, his LIDDA Service Coordinator, Service Coordinator Supervisor, the MDS Coordinator and the very new Activities Director from the nursing facility where he lives, and reviewed available records.

JM is a very sweet, soft spoken, tall, and thin 69 year-old gentleman who seemed to enjoy our visit. He has a sister in law and nephew he sees, "once in a while." His two brothers have passed away. He has a great sense of humor. He is very neatly groomed and dresses wearing stylish cowboy boots and his special belts. He used to work on a farm bailing hay. JM arrived at the nursing facility on January 13, 2013. He was transferred to the nursing facility from a hospital where he had been treated for heart disease. Prior to this hospitalization, JM said he lived independently, though his past service history is unclear; according to the LIDDA staff he may have received some community services and supports at various times. He has a pace maker, and one of his key concerns is to maintain his health, especially his cardiac health. He also developed Diabetes Type 2. The staff at the nursing facility help him with his medication.

JM grew up in a small town about 10 miles from the nursing facility. He struggled somewhat with time concepts, and could not assign any kind of timelines to events in his life. He also could not recall why or when he came to the facility. However, he reported that prior to living in the nursing facility, he spent a lot of time alone and that he lived alone. He worked as a dish washer at one point and also as a janitor. He also liked walking along the road looking for coins. He reported having some sort of disabilities-related services when he was in the community. He was quietly firm about wanting to stay where he is. Though he participates in many activities at the facility, he stated that he did not have any friends there. However, he reported that he enjoyed Bingo and sometimes Dominoes. He used to make jewelry, but doesn't any more. He later showed us his jewelry (beads he strings onto fishing line). He likes 60's music and there are music performers there on Monday nights. He also enjoys doing puzzles and seeing John Wayne movies (he has a collection). When asked about going out, he said he sits outside sometimes and watches the squirrels. He expressed greatly enjoying a recent visit to a museum. He also enjoys fishing, but has not done this for some time.

JM did not receive a comprehensive functional assessment of all habilitative areas that accurately identifies all of his strengths and needs. He received typical nursing facility assessments, such as ones done by his physicians, the MDS, and he has a nursing care plan. There is a PASRR Evaluation (also known as "PASRR Level II") completed on January 20, 2015. This was two years after he entered the nursing facility, and did not identify any areas in which JM would need assistance. Only PASRR service coordination was recommended. I could not find any earlier PASRR Level II documents to review but notes in his ISP and forms called PASRR SS Forms suggested the SPT only recommended NF OT briefly for a shoulder problem in 2015 (see below), and service coordination. I did not find any documents providing details regarding his self-help development, a cognitive assessment (despite a diagnosis of dementia noted on an ISP, and a diagnosed intellectual disability), independent living skills, or social development. This is unfortunate as he would have benefited from services that address areas in which he was documented to have lost skills and have needs, such as performing ADLs independently. Specifically, JM would benefit from assessment and interventions in numerous PASRR supported areas including: OT aimed at maintaining independence in his daily living skills, PT to address his complaints of knee pain, ILST to maintain his integration into the life of his community, and possibly a move to a supported living situation in the community.

JM is only receiving one specialized service: service coordination. Based on my review, he is not receiving all necessary PASRR LIDDA and nursing facility specialized services with the appropriate intensity, frequency, and duration, to address all need areas. As noted above, the assessments done were insufficient in identifying what PASRR services would have benefited him. Beneficial services should include services that maintain as well as teach skills. His June 17, 2015 ISP, noted that the only specialized services he would receive was service coordination. The only desired outcome listed was that he wanted his shoulder to feel better. The plan was to request a PT evaluation. In this ISP it was also stated that "I do not need any help with communication," "I do not have any clinical needs," and "I need the nurses to give me medication." Based on the records and my interview with JM, I am troubled as to why a person with his profile should be living in an institutional setting, and doing so without any effort to transition him to the community by providing him with various specialized services.

As of the time of my review, JM had been institutionalized for close to five years. The longer someone is institutionalized, the harder it is to leave. His ISP update from 3-16-17 included the statement "I am very independent on all ADLs." Then, three months later, in his 6-15-17 ISP document, it is stated that he has dementia and mild ID, and diagnoses were added to the discussion including Diabetes Mellitus Type II and edema. He was also noted as having a mild hearing impairment. These were all newly cited concerns in the updates and ISP meeting and SPT team discussions, since his March 2017 ISP update. The statement in the June 2017 ISP, "I am unable to bathe independently" therefore either represents a departure from prior functioning where it was clearly stated he was completely independent, or at best inconsistent reports of his level of independence since there was a prior reference (June 2016) in an SPT note that he needed help bathing. I believe he could benefit from OT to promote improved daily living and self-care skills. He also could have benefitted from PT at least starting when his knee problems and fall risk were being observed and documented by his SPT. He had apparently been assessed as not needing any PT but had problems with his knee, which were evident and bothersome to him when we visited. These problems are also referenced in his June 15, 2017 ISP update, where it was also noted that he was at risk for falls. He stopped several times when walking with us, because of his knee pain, and rubbed his knee and frowned. He said he would accept help to do special exercises for his knees if this might assist him. He also noted that he liked therapy and that he had it once before. His loss of skills is concerning, given his lack of nursing facility PASRR services, and his desire to be independent. A day program or ILST services would provide him with opportunities to be in his community and to be learning or rehearsing skills for more independent living. It was noted that he likes to go out into the community. However, he reported limited community outings from the nursing facility. Though he has declined to attend a day habilitation program and says he does not want ILST when asked, it is not clear that JM is able to make an informed decision about these services. He certainly could have had individualized supports or ILS and have had an individualized schedule of activities that included regular outings, like fishing or going to the movies, which he expressed interest in.

JM does not have a professionally-appropriate ISP that was developed based on a comprehensive, person-centered assessment that includes all needed services and supports to successfully transition to the community. I do not feel his ISP was comprehensive as there are key areas that were not fully addressed as noted above. Without all of the necessary assessments, an appropriate ISP cannot be developed. He was not provided with individualized transition planning and barriers to transition to the community were not addressed in documentation provided. For example, in the CLO section of the ISP, barriers to community living were not defined and it was reported that he, "is well taken care of" at the facility, and "has nowhere else he would want to go." None of his needs for community living were documented. According to LIDDA staff, one of the reasons he reportedly declined community services was that the services he would need are not found locally, and he wishes to remain close to his hometown. The services that are needed should be described to the individual, and related goals should be developed regardless of the current availability of such services. JM lives in an area without many services and as a result, has not been provided the opportunity to fully learn what could and should be available to him. It is unclear why these barriers are known but not documented, so that the full SPT could be addressing how the barriers might be overcome.

JM is not receiving active treatment. This is clear based on the above information. He has not received adequate treatment to promote his independence, to maintain his skills and functioning and to allow him to function with as much self-determination as possible. The largest concern I have is to understand why he was not getting out into his community, and being helped to plan some way of living in the community. In summary, without adequate comprehensive functional assessments or appropriate specialized services, he cannot be receiving a program of active treatment.

I believe that JM would benefit from living in an integrated setting with appropriate community services and supports. He could be adequately and safely served in the community and would benefit from having opportunities in the community to socialize, participate in various community activities, and do the things he enjoys such as going fishing, going to museums and walking outside, among other things. His LIDDA staff stated that they believed he could benefit from living in the community and could benefit from ILST and his PASRR Evaluation states that JM is not appropriately placed at his NF noting that “Client does not require 24-hour care. He would be able to function in the community with appropriate supports in place.” His records state that he moved to a NF because of an acute illness; he has clearly never left. The reason JM has not left the nursing facility is likely due to his lack of understanding regarding what his options are, and also because of a general tendency for people to be anxious about change after a scary health event. His case is an example of how people with ID can end up becoming “institutionalized,” as the easiest thing is to just stay where you are and come to view that is the best one can hope for, especially if historically, community experiences were negative.

Based on the above, I do not believe that JM made a fully informed decision to remain in a nursing facility. In JM’s CLO forms, there was no new information documented between the first one dated January 20, 2015, and the most recent CLO form dated June 15, 2017. The documentation provided did not include a description of barriers for community living specific to JM, nor did it specify how one might address these barriers. There was also no detailed description of what would constitute an effective set of services that could best meet his needs and be responsive to his interests and preferences. I believe that JM is relatively happy in his placement now, and that people there like him. I worry, however, that he is not making a fully informed decision, and that he could be receiving care that may have prevented skill loss, and promoted a better quality of life. It is clear when speaking with him, that when speaking about community living, JM does not engage beyond stating he does not want to leave. JM’s LIDDA staff agreed with this assessment and noted that they did not think that JM really understood what it might be like to live in a community placement. They shared their view that a major barrier would be that he reasonably wants to live in the locality/area where has always lived, and that there are very few resources in this area. Though JM has expressed interest in remaining in the facility, his LIDDA staff felt that he might change his mind if there was an appropriate local option. This would also provide a setting that he could see and experience before making the decision, rather than having this be theoretical. His service coordinator also agreed that he has not had adequate time to build enough rapport and trust with JM to know if that would help him to engage more in learning about his options. Continued institutionalization in a nursing facility is neither necessary nor appropriate for JM. I was extremely puzzled and surprised when I met him that he was living in a facility based care setting. Without adequate decision-making supports and a concrete understanding of what community life would be like following years of living in an institution, it cannot be said that JM has made an informed decision to remain in the nursing facility.

JuG
Date of Visit: September 5, 2017
Interviewed JuG and spoke with his service coordinator, a representative from the LIDDA, as well as the social worker, the MDS coordinator, and the rehabilitation manager at the nursing facility. I also reviewed available records.

JuG is a 64-year-old man who has resided at his current nursing facility since December of 2013. He is diagnosed with a moderate level of Intellectual Disability, Cerebral Palsy (CP), anemia, acid reflux, hypertension and a seizure disorder. He reportedly has lived most of his life in facility care of one type or another (state run facilities, nursing facilities) but he was at least at one time in a group home. He was listed as having been admitted to the current facility from another nursing facility. JuG also had a diagnosis of dementia listed in his records, which seems to be a common diagnosis among the people with ID in nursing facilities that I reviewed. However, people we spoke with had not seen any real change in his cognitive abilities, which is a critical component of dementia. JuG reportedly had a spinal meningitis as a child which led to his paraplegia, and likely also his ID. He had surgeries to his legs and has club foot affecting both feet. He was a little difficult to understand due to dysarthric speech, and a long latency to responding. JuG is a very sweet person, but shy about stating his views and expressing what he really wants. He answered a few times that we should “ask FG” (his brother but not his guardian) and he also asked me what I thought, when I asked him about whether he might consider looking at a community living option. When given a lot of support and reassurance that people really want to know what he desires and thinks, JuG will say that he very much wishes he could go to a day program and he would like to live in a community placement. However, reportedly, his brother tells him he needs to stay where he is due to his medical concerns as his brother worries about a community setting being able to manage his care. This is because of very bad past experiences when his brother had to remove him from a group home that he felt was dirty and not taking proper care of JuG. His service coordinator has noted that JuG often defers to what his brother wants. His brother, for example, reportedly decided that JuG did not need a phone of his own, though he has had one before and would like to have one (despite needing help to use it). Apparently, nursing facility staff agreed that he did not need his own phone because he can use the facility phone. They reported that they “allow” him to make calls. JuG’s service coordinator tries to remind JuG that these decisions are his.

I do not believe that JuG received a comprehensive functional assessment of all habilitative areas that accurately identified all of his strengths and needs. The only Level II assessment I could find was dated 12-18-13 and did not identify him as having an Intellectual Disability (only a Developmental Disability), despite his diagnosis of Moderate ID. Only Service Coordination was recommended despite his many areas of challenge that subsequently were understood to require comprehensive assessments and specialized services. Though there were nursing assessments and OT and PT assessments, he did not have a number of assessments done to inform his treatment planning in a coordinated manner. For example, he had an OT and PT assessment in early fall 2016, but had a Speech assessment only much more recently, based on records available for my review.

Assessment of all required habilitative areas and needs should have included much more detail regarding his self-help development; affective development; speech and language development; auditory functioning; cognitive development; social development; adaptive behaviors and independent living skills;

and vocational skills. I did not see these assessments in the records I reviewed. I did not find a detailed description of what he would need to transition into community life.

I do not find evidence that JuG is receiving the necessary nursing facility and LIDDA specialized services, with the appropriate intensity, frequency, and duration to address all need areas. Although he has reportedly been receiving some specialized services, the intensity and frequency seems inadequate given his profile of areas of need. There was a pattern of these services when provided, to be stopped and started with gaps of time without needed services, and often he received restorative services (rather than skilled services from an OT or PT). It was documented on a PASRR Specialized Services form dated 7-7-16 that JuG made no progress when he participated in restorative services last quarter, which seems unsurprising as these services (restorative) are not provided by professionals and JuG has some very complex service needs in the areas of OT and PT. JuG asked if he could have OT and PT and there was an agreement at the meeting to provide these services for “contracture management, sitting position and ROM.” At the June 2017 Interdisciplinary Team Meeting, the IDT notes state that the team determined that specialized services were indicated. It was recommended that JuG receive PASRR NF specialized services including OT and PT. The NF plan of care, dated June 28, 2017, stated that JuG would be screened for speech therapy services. It did not appear that the screening for PASRR speech therapy or other specialized services were recommended on the June 2017 IDT. This is despite it being documented that JuG “mumbled.” Further, it was noted in my discussions with the SC and NF staff at the time of my visit, the he is sometimes difficult to understand. The only LIDDA specialized services that JuG was receiving at that time was service coordination.

According to the records, JuG received PT intermittently over the past few years. He had PT in 2014 for a 2 month period, as documented in the PT therapy note from 9-2-16. PT notes showed that he was again receiving PASRR PT between 6-23-16 and 9-2-16, after which he was being discharged for “requiring a lower level of service”. There then appears to be a break in these services for more than six months, between 9-2-16 and 3-17-17. Since March 2017, it appears the services were continuous through September 1.

However, it appears as if PASRR PT was not provided continuously. A 9-30-16 quarterly review of his ISP noted that he was discharged from OT 9-20-16 as well as PT on 9-2-16. It was then stated “therefore, these SS will be removed from his PSS today.” Nursing facility staff reported that JuG “reached his potential with OT and PT.” The PSS of the same date stated he reached his potential. The only specialized services recommended then were Service Coordination.

In his 12-29-16 ISP annual meeting note, it was stated that he would not be receiving any Nursing facility specialized services for this year but they would assess him for changes. There are no notes at all that I could find about LIDDA Specialized Services, but only Service coordination is to be provided.

As of the 3-15-17 ISP, JuG’s SPT agreed that he needed PT and OT assessments and that strengthening was a concern, and discussed using pillows or cushions in his wheel chair as he has had a decline in his functioning and slouches in the electric chair. It was noted that he loves his electric wheelchair, but he is currently using a manual wheelchair due to safety concerns. According to the nursing facility staff, this restricts his independence, but they were concerned that he might slide out of the electric wheelchair. Additionally, JuG was considering attending a day habilitation center but the nursing facility staff also raised concerns about his going to a day habilitation program because he would need to be changed there, and this requires a Hoyer Lift. The NF staff somehow erroneously believed that JuG had to be continent to attend a day program, which is odd since day habilitation programs are designed to assist people who have a variety of physical challenges including people with neuromotor problems and issues with bladder and bowel control, and who need to be lifted out of wheel chairs.

Goals were set for specialized Services of OT and PT to gain strength so he can once again use his electric wheel chair, but not for exploring his getting to the day habilitation program. OT Specialized Services were provided between 6-23-16 and 9-20-16. These were again provided starting in March of 2017, and are ongoing to the present time. Under discharge plans in the OT note from June 2016 it was simply stated "nursing care." On a 6-27-17 PSS form, Specialized OT and PT were checked off for Nursing Facility Specialized services, but only Service Coordination for LIDDA based services. The comment section included a notation that he did not want to move and that he would continue to get specialized Nursing facility services of OT and PT.

An ST note dated 6-29-17 showed he was assessed and started ST to address his communication challenges which was a very positive step, and one he could have benefitted from for a long time prior to this.

His 6-28-17 IDT stated he does not want community living and will continue to receive OT and PT Specialized Services, but does not reference ILS, or Speech Services. This is puzzling given his profile and preferences. He wants to be going out into the community. He has talked about missing community settings.

I did not see evidence of specialized services being in either his ISP or nursing care plans to the extent that he needed them to be. One of his Nursing Facility Care Plan (NFCP) goals with a listed start date of 1-5-16 was that he should "have positive experiences in his daily routine without overly demanding tasks and without becoming overly stressed." This is an example of a "staff centered" rather than a person-centered goal. Another goal at the time included achieving maximum wheel chair mobility but to do this by following OT and PT recommendations, and not by having PASRR services to address these.

His Nursing Facility Care Plan (NFCP) notes dated 3-15-17 were brief and stated that he "prefers" to urinate into a diaper because he does not want to have to be put in bed for changing. Actually, he fears going back to his room into bed and then needing assistance if he wants to be up and out of bed again. Some staff stated his attitude is not sensible because he can get right back up if he wanted to. Others stated that it is likely he has experienced being left isolated in bed, and not having easy access to assistance to get back up again whenever he wanted to. There was a time when he was given scalding hot coffee, spilled it on himself, and then was restricted to staying in bed for an extended period of time because it was felt that his wounds would not heal if he was up in his wheel chair. His refusing to go get changed (which occurs in bed), and attempts to control going back to bed in some way, suggest he had previously been unable to choose being up or not being up, and that he did not want to remain in bed alone for long periods because of his disability. This is an example of how people develop "behaviors" that are viewed as inappropriate such as his refusing to go get changed.

His electric wheel chair is not being used due to the slouching problem. I would note that this seems to have emerged as a problem and was related to an issue of his strength, after a period of almost one half of a year when his NF Specialized OT and PT services were not being provided. It is noted he would like to attend a day program but that at present, there are not any concrete plans. In the 4-6-16 note, he is described as having clear speech which is very odd. He does not have clear speech, and very correctly finally received Speech Therapy that seems to have started in June of this year. "No specialized services are needed at this time," was stated. As noted above, he did finally get needed Specialized Services for a short time in 2016.

I do not believe that JuG has a continuous active treatment program that includes aggressive implementation of a program of specialized services that has been directed toward the acquisition of the behaviors he needs to function with as much self-determination and independence as possible. He often defers to others, and he does not tell people what he really wants or backs down from pursuing his own wishes. I believe he has developed what we refer to in my field as learned helplessness. I believe he has not had all of the help and services he needed to prevent further regression to the extent possible. As described above, he did not receive a comprehensive functional assessment and the specialized services he has received have been intermittent, interrupted by large gaps, or altogether absent. He did not receive services that focused on promoting his independence in a continuous way, and likely he could have been making more progress if this had been done.

I do not believe JuG has a professionally-appropriate ISP that was developed based upon a comprehensive, person-centered assessment and that includes all needed services and supports to successfully transition to the community. There were many missing assessments upon which such a plan must be based. I do not feel that the topics of his individual interests, strengths, needs, preferences, concerns, and barriers regarding community living, have been fully addressed. Also, many statements made by his caregivers reflect a lack of an understanding person-centered services and supports. For example, saying that you "allow" a person to make phone calls is concerning because he has every right to make phone calls. Though he may need some help to make a call, he should not need permission to make phone calls. Another example was a nursing facility staff declaring his wanting certain things as unreasonable, such as the fact that he wanted a telephone and that he wants to go out frequently; and said…"he constantly wants to go out," (as if this reflected a problem behavior on his part). I believe that all such statements reflect most likely inadvertent but negative outcomes of institutional life that are of the type of things that previously led to development of guidelines and regulations promoting sensitivity to the individual's needs, interests and preferences and to a focus on being sure every single person served has an opportunity to live in the least restrictive setting possible.

There was documentation of staff blaming him for urinary accidents he could not control (stating things like he prefers to urinate in his pants). This is a common problem in institutions where such occurrences cause extra unpleasant work tasks for staff. I am concerned that barriers to his living in the community were not addressed fully (except in the past-see below), and the ISP reflected no examination or documentation of the services and supports he would need to live in the community. In general, even with the existing ISP, I did not see implementation of the ISP to be consistent with his needs and preferences. Yet another example is found in his ISP profile (section 5) where it is recorded that his personal strength is that "People like and admire that JuG is cooperative and friendly." This too is a common institutional response in that doing what you are told to do and not challenging the staff is valued. A true personal strength of this man might be that he is caring and considers what others want and think (maybe to a fault). He is very gentle and seems kind hearted. Listing compliance as a strength is not representative of a person-centered approach.

I believe that JuG would benefit from living in in an integrated setting with appropriate community services and supports. People with very similar needs to those identified for JuG, however, are safely and happily served in community based settings. His new service coordinator said to me that he would know if he wanted to go to a group home because he was in one once. This can lead to an assumption that there is no need to help someone with past negative experiences to understand that these are not representative of all possible experiences.

JuG would benefit from living in the community because he would have much more access to the things he states he enjoys, and because he has asked to be able to do so. He has lived in the community in the past and there may have been issues and concerns, but he is very clear that there were also joys for him, and opportunities he now wishes he could have again. Everyone I spoke with (his old and new service coordinator, his MDS coordinator, his other nursing facility staff) felt he would benefit from having more access to activities. His MDS coordinator stated that "I just wish" he had more to do. All felt he would do well in the community.

Of note, a CLO form filled out in August of 2014 (and several after this) are the only ones I have reviewed among many, in which a Service Coordinator really tried to understand, document and address barriers to community living. This demonstrated that this can be done but that such efforts are not being made very often. In this CLO, however, the Service Coordinator treated his brother as the LAR. In the CLO, she explained that JuG's family was very worried about trying a community placement again because past experiences with a home that he said was "filthy." She documents in some detail exactly what reassurances she provided to the brother (which she did think was an LAR) and to JuG. She also noted that JuG "would like to live in a group home" in the town near his "family and friends, and to have access to the community." She clearly documented that JuG "did not want to stay at the nursing home" and that "he missed going to the Adult Day Care center and going on outings on the weekends." His brother again stated he did not want JuG to go back to Corpus Christi though the service coordinator explained this would not be necessary and that there were local options. She concluded that in her professional opinion, JuG would be "much happier if he were in a setting with individuals he could relate to, and be able to interact with them and participate in activities with them." She also stated that she was concerned that the family was not honoring JuG's true wishes. She stated she would continue to try to assist him to get a community placement. She also stated she would recommend PASRR Specialized Nursing Facility services of PT, OT and Speech though I am uncertain as to whether these were provided at the time. The next two CLOs, also very well documented, revealed JuG had the kidney tumor and surgery and for a time, was himself fearful of leaving the facility. However, he later admitted he missed community life, but seemed to defer to his brother's wishes. In the July and December 2016 CLO, there is barely any documentation about barriers and possible remedies, despite his history and this coincided with there being a new Service Coordinator.

I do not believe that JuG has made an informed choice to remain in a segregated nursing facility. In his 12-29-16 ISP annual meeting note, there is documentation that his brother feels the nursing facility is the best place for him because of his medical needs. It states that JuG is choosing to stay, without recognizing that he has issues saying anything that contradicts his brother, and that his brother is not actually his guardian. The space on the CLO and the ISP to input barriers to community living and how might these be addressed was left blank in this document, and there is no documentation that his team discussed such issues or ever considered what might be needed to provide safe and positive supports to him or to transition him to a less restrictive setting. The 9-30-16 PSS form similarly stated he no longer wants to pursue living in the community, and also that he reached his potential.

I believe that the circumstances leading to JuG's admission into a nursing facility (a negative experience with one group home) has colored his brother's thinking, and he in turn, has a strong influence over JuG's willingness to purse things he otherwise would like to pursue (day program, placement in the community). The facility social worker stated that though JuG's brother cares very much, JuG's brother did not always seem completely clear on issues she presented to him and she confirmed JuG's brother is not his guardian. When asking him what he really wanted, JuG would constantly say, "ask my brother" or "what do you think I should do". I believe that the past negative experiences in the community have influenced JuG and his brother's views. His brother appears to see the Nursing facility as a safe place, because of his brother's medical history. In early 2015, it was discovered that JuG had a tumor on his kidney and he subsequently had surgery to remove it. He has been fine since then but this was an additional scary event adding to the sense that only a medical setting is safe for JuG. I feel that there were additional steps that should have been taken that could have addressed the true barriers to his living in a community setting. For example, through counseling which can be provided by some behavior specialists, JuG may have been taught and had behavior shaping techniques applied to develop more skills in expressing his own views. Staff guidelines might have been developed to help them understand how to make their priority understanding and respecting his opinions. He may have also been helped by more detailed review of options using multi-media. He and his family might have been assisted to connect with peers and other families where there has been a positive and successful experience for a person with similar disabilities in achieving placement in a less restrictive community setting, to the extent that they influence him. A visit to see community placement options might have been arranged for JuG or for him and his brother, and video recordings can also be used. I also believe it is important not to ignore what JuG wants because someone from his family has a different view, and that the commitment shown by the Service Coordinator in 2014 should be the norm.

Having consistent LIDDA specialized services such as attending a day program or having ILS also may have enabled JuG to further experience and develop skills for community living in settings that were not like the one from which he was removed. This may have broadened his brother's perspective. I do not believe that he or his family have been given sufficient information to understand community living due to the lack of understanding that a single bad experience need not define all future possible experiences and that people just like JuG live in safe, clean and very positive places in the community. I do not see where they have been provided with the level of detail needed to really understand this, and how exactly his needs could be safely met in an integrated setting. The section on his ISP updated form from July 2017 where there could have been a detailed description like this (part 2 of section 9) is blank.

In summary, I do not believe that JuG requires continued placement in an institutional setting, and that doing so has a negative impact on his well-being and his quality of life.

KD

Date of Visit: August 23, 2017

I conducted interviews with KD, his guardian (uncle), his LIDDA Service Coordinator, his Nursing Facility Rehabilitation Manager, Social Worker and MDS Coordinator. I reviewed records provided.

K.D. is a 43-year-old man who has a congenital form of a highly heritable disease Mytonic Dystrophy Type 1, which his mother also had. This disorder affects his movements and overall motor functioning and is usually progressive. These problems greatly impact a person's ability to be independent and their quality of life. Myotonic Dystrophy can vary in terms of the extent of its impact on functioning and various therapies can help slow the progression of problems, such as muscle weakness and stiffness. Preventing any loss of movement control and mobility is very important. KD is now using a wheelchair. He has some swallowing problems as well. He has lost capacities over time, especially since he has been living in Nursing Facilities. KD has been in the current facility since 11-15-14 and was at one other previously, where he lived for a time at a nursing facility also serving his grandmother. I met with KD and his guardian, his uncle, who is a tremendous advocate for KD and is very involved in his life. KD greeted us enthusiastically and warmly. He loves to socialize and meet people, and likes being active. KD is repetitive (which at times seems an issue for staff). His speech is difficult to understand due to a dysarthria. He has a sense of humor and laughs and smiles frequently. He has an especially humorous banter with his uncle. One time, when asked why he liked to go to therapy, he said "…to meet girls!" KD was previously involved in Special Olympics and noted his desire to maintain his involvement even though it would be just to watch, since his decline in mobility over recent years has led to his belief he would not be able to participate. KD's uncle lives nearby and visits him often.

Based on my review, KD has not received a comprehensive functional assessment that includes all habilitative areas and that identifies all of his individual strengths and needs. Some of these areas are addressed, but there was not a detailed assessment of his speech needs, following admission to the current nursing facility in his first ISP/SPT Planning meeting. At this 12-11-15 ISP/SPT meeting, it was reported that he "did not pass" his speech test and that this won't change so he will not need any ST. This is referencing a swallowing evaluation and indicated the need for a pureed diet. There was not any reference here to his speaking difficulties. I did not see an initial functional behavioral assessment (and never found this to have ever been done). There was no documentation that anyone evaluated his habilitative needs with respect to social skills, though there are notes suggesting he had ongoing challenges such as those related to his interactions with others, resisting care, and his anxiety around his health.

There was not a detailed assessment to address what kinds of community activities and independent skill-building he would benefit from most, nor a mention of related goals. An assessment of possible community based day habilitation programs was also not documented. He had a PASRR Level 1 screening on 10-22-15. KD's PASRR Evaluation (PE), dated 10/23/15, confirmed that he was PASRR positive for ID, DD, and MI. The PE indicates that KD needs assistance with nutritional support, self-monitoring and coordination, assistance with medications, activities of daily living and independent living skills. Despite these support needs, the only specialized service recommended on the PE was service coordination. KD has not received all of the LIDDA and NF specialized services from which he could benefit. His uncle has been asking for specialized services for quite some time but has met with resistance from the NF staff.

He was admitted to the previous NF in April 2014, and was evaluated by OT and then received short-term OT services through Medicare Part A. PT services were provided in May to July 2015 funded by Medicare Part B. Of note, KD was able to ambulate using a rolling walker at this time so it is unclear why there was not more of an aggressive attempt to help him maintain more mobility, or at least not to lose functional skills. This makes the termination of skilled PT a concern as this may have contributed to his reduced mobility and concomitant loss of independence over time, or to the conclusions drawn that it was unrealistic to expect him to walk again made in February of 2016 at the quarterly IDT meeting. This round of PT seems to have ended on 6-18-15. He received "restorative services" which do not include skilled services directly from a PT. The PT goal was to have him retain highest level of functioning through the restorative care program. In October 2016, KD was screened by the NF therapy department for specialized services and was deemed ineligible for any services beyond restorative services at that time. A PT note dated 6-6-17 showed additional PT services provided for one week in June 2017 under Medicare Part B. It was noted under "Previous Therapy" that he had 2 weeks of PT in January 2017.

There is a February 12, 2016 PASRR services approval note for 12 weeks of OT. He does seem to have received PASRR funded habilitative OT services during this time, and at some points previously. I cannot determine if he had OT services continuously. As of 2-17-16 quarterly SPT note, he was reportedly receiving OT and PT through the "restorative program," indicating he was not receiving skilled OT or PT at this time. The 4-19-16 PASRR PSS Form identified only ST and SC services. A 2-16 ISP/IDT quarterly update noted he had been receiving "restorative" OT and PT services, but that he was approved for PASRR OT to start that day (A PASRR specialized services request form is also in the records dated 1-18-16 and another renewal on 5-4-16). Although, KD may have received some habilitative PASRR OT services at the time, those services were intermittent and not ongoing as of his most recent ISP update, 7-10-17, which, in the SPT summary, states that KD was in not receiving specialized services at the time but they were trying to find a staff to provide ILS. In the 1-13-17 update, there seems to be confusion, as it was documented that he got 2 weeks of specialized PT "because his Medicare Part B funds became available." It may be that the Service Coordinator does not understand the difference between the SS funding for OT and PT versus Medicare-funded short term non-habilitative treatment.

Following his hospitalization in June of 2014, KD had an evaluation for restorative OT that was funded by Medicare part A. This evaluation was related to his need for help and that without this, he would likely suffer a decline in functioning. It was noted that KD was treated with an antipsychotic drug at the time, which is a major concern, given that he had no behavioral treatment services. Under the category of "Precautions", KD was listed as being on a room restriction due to having C-Diff (a very contagious infection). Work was done on building his strength and self-care independence. It was documented that his goals were met on 7-29-14 leading to discontinuation of these services. It appears from the records that the OT was expecting KD was going to return to his group home, however he ended up staying at the NF and did not get habilitative OT, which may have been very helpful in preventing skill/strength and declines

KD had a Speech Evaluation related to dysphagia between June and August of 2014, resulting in the development of aspiration precautions and a modification of his diet, (he had a Modified Barium Swallow Study). This change in diet was likely difficult for him since he could no longer enjoy certain foods, and he was noted to seek food he should not have after this change. This was funded through Medicare Part A. A second swallow study was done at the request of the guardian to see if he could have an upgrade from pureed to mechanical soft foods. This was funded through Medicare Part B. His 12-11-15 ISP profile noted that he can be difficult to understand and gets frustrated about communicating and expressing himself. It is therefore puzzling as to why he has not had more consistent speech therapy services. Being able to communicate is a foundational skill area for quality of life and promoting independence. Later, he did have some ST with a start date of 3-29-16 through Medicare Part B for improving his articulation. However, this seems to have been initiated because of reports of skill loss or decline in functioning in this area. Previous therapy/assessment was noted to only have been provided for his swallowing problems, despite his long term challenges documented to his speech and communication. KD's 8/16/16 ISP stated that although KD had been receiving "habilitative speech therapy" in order "to increase clear communication." Yet this too was discontinued in July of 2016. Direct Medicare funded ST was apparently going on at least through some point in June 2017. These services were not continuous as was needed to help him build and retain skills.

Overall, the lack of ongoing and consistent habilitative services is especially concerning given that he seems to have lost abilities and independence, as it is important for people who have conditions like his to have ongoing interventions to prevent skill losses and maintain abilities involving movement and motor control.

There have also been barriers that have prevented KD receiving LIDDA specialized services which include difficulty finding and retaining a worker who can take him into the community and support his acquisition of community living or independent living skills (ILST). A further barrier is that his Service Coordinator admitted she was not aware of all of the options open to KD, and noted she had received no real training (apart from shadowing another service coordinator for a week) as to what specialized services were available or what constituted active treatment, such as Behavioral Support Services. Statements found in key documents, also suggest that his team sees his long-term care in a restrictive setting as adequate. For example, in an evaluation dated 12-11-15, his Service Coordinator wrote that "[KD's]'s needs are met at the NF," "he has access to all physical, emotional and behavioral health considerations." In October 2016, KD's team discussed that he would not benefit from day habilitation programs because he does activities at the NF. Attending an activity at an institutional facility is not the same as one being integrated in the community. This is especially concerning given KD's express wishes to be able to be out in his community more often. Even in the team discussion, it was agreed that he could benefit from, and wishes for, more community involvement.

At a 2-16 ISP/IDT quarterly meeting, his LAR apparently disagreed with the NF staff wanting a psychiatric consultation as KD is anxious *when he has GI pain*. He advocated for pain relief as the alternative approach. These concerns are as stated, ones that a behavior specialist could also address using positive supports to teach relaxation skills, increase his asking for help and other similar approaches.

KD's LAR was not asking for day habilitation as a specialized service through the LIDDA only because of the past negative experiences he had with this, and his perception that a better option was not available in the local community. Regulations require that services that are needed are documented, not services available.

Given the above, KD was not receiving active treatment, since key treatments were intermittent. While it is good that KD is reportedly relatively happy at the NF, it was clear from everyone who knew KD that they all agreed that he would benefit from more community involvement, and from services that would assist him in maintaining his independence. The most significant barrier to KD's receipt of consistently delivered habilitative services relates to their understanding of when and how such services should be provided. The NF staff acknowledged that they consider PT, OT, and ST as services that should be offered when and if there was a marked decline, and not for maintenance. This was true despite the guardian telling me he had wanted specialized services to be provided. KD was not building skills to prepare him for community living or to maximize his independence on a consistent basis. As noted above, he received services virtually only through Medicare part B intermittently in reaction to episodes of functional decline.

KD's guardian stated to me that he knew that KD would end up in a wheelchair when admitted to a nursing facility, even though he might still be able to walk. KD's guardian believed the facility would be "risk avoidant" around his abnormal gait and fall risk and ask KD to use a wheelchair to avoid any falls. Despite past health problems, he felt KD may have continued to walk if provided therapy and if there was not such concern about his falling. He even believes KD may walk at times in his room.

As noted above, there had been resistance to providing ST, OT, and PT through PASRR from the NF staff. I discussed this subject with the Service Coordinator and Rehab Manager (with input from the MDS nurse coordinator) and they confirmed that they have not felt that KD needs such services, despite his history and current challenges to maintaining strength, prevention of increased neuromotor symptoms such as contractures and potential for worsening swallow and articulation. Further, the Service Coordinator stated that ultimately, whether or not KD could get the requested PASSR NF services were up to the rehabilitation staff. Furthermore, although his current LIDDA Service Coordinator (who started October 2016) had advocated for specialized services for KD on behalf of and with his uncle, she did not know which behavioral services were included among the LIDDA specialized services options. Unfortunately, no adequate training was provided to the NF staff regarding people with IDD, PASRR, and habilitative care.

KD does not have a person-centered ISP. For example, the goals listed in KD's ISP such as 4-4-17 ISP note "KD is stable and a favorite of the NF staff" whereas KD's goals have been to get out more into the community. Being a "favorite of the staff" would seem to reflect the facility staff's concerns that he behaves well. The setting of expectations for KD's life seem very low, and yet, he and his LAR seem to want more for him based on my meeting with them.

KD would benefit from living in an integrated community setting with appropriate services and supports. He is a younger man living with mostly people who are much older. He loves to be busy and though he has some activities at the facility, he is not engaged in a structured day. He has presented with challenging behaviors that likely impact his quality of life that are not being treated appropriately such as repeatedly seeking out food he might choke on. I believe he has likely lost strength and will experience reduced independence as a result of the failure to implement the PASRR services for which he qualifies and could benefit. The apparent lack of a good fit for him in any local existing program has been a significant barrier. The documentation stating that his LAR wants him to stay at the NF should be clarified to state that, as long as there are not any appropriate options in the community, he does believe the current facility is better than where he was before because, there he became very ill and nearly died. Given this, there should be a detailed review of the barriers to providing KD with a less restrictive setting, in a place meeting the criteria set out by his LAR which were very reasonable and consistent with policies for anyone with IDD getting placed into a paid care setting. These considerations were not clearly documented or elaborated upon in the CLO. For example, the CLO form dated 4-14-17 notes that the guardian "is very intelligent and aware of options." The guardian wants KD "to stay in NF." In discussion with this guardian, he does not feel this is the best plan, as noted. KD's uncle did not like the day habilitation programs which he misunderstood as being mandatory at group homes. It concerned him that group home staff blended sandwiches in a blender to accommodate his need for a pureed diet.

It is my opinion that KD's guardian has made an "informed choice" to have KD stay at the nursing facility for now, but he wants his brother to have a higher quality of life in his community so he was not as it seemed, satisfied that the current placement is optimal and preferred to a life in the community. He simply does not feel better community options exist presently. The issue is that the guardian has not been provided with reasonable options for safe community living, nor have the barriers (appropriate, safe setting) been addressed. This results in his not being truly fully informed. Details regarding these barriers and what work will be done to remove them are not documented in his CLO, nor does his ISP address ways to prepare him for a life in a community setting. His CLO form 5-20-16 shows all of the boxes marked to indicate the documents required to be reviewed were provided on 11-12-15. However, other sections, such as Educational Activities section (where the professional is asked to list all the CLO education and exploration activities offered to the individual/guardian), and the Community Visits section were both left blank. The issues and concerns section only noted that "KD has lived in a Group Home and it was not a good situation" and also that KD is and his guardian are aware of options. There were no discussions regarding overcoming the above-noted barriers (appropriate, safe setting). These documents suggest a very limited view of the role of the SC in helping KD and his guardian overcome barriers to achieving a life in the least restrictive setting possible. It would have been important to outline what an appropriate and safe positive setting and set of services should look like for KD, but none of this was documented. This seems critical to addressing barriers and fully informing the guardian about options, so that he can make a truly informed decision.

KD’s guardian shared with me that he remained concerned about finding any appropriate options in the community that would meet his nephew’s needs. Outlining the features of a community home that would be acceptable to him, he listed: a nice area, staff who are caring (“people who really care”) and would help KD be active and engaged, staff who are skilled/trained to provide skilled and safe and effective care, and a peer group with whom he could speak and possibly make friends (in his past home, all of the residents were non-verbal). These features are basic and should be considerations for any person with IDD seeking a new home in the community.

MM

Date of Visit: September 5, 2017

I Interviewed MM, her sister, MM’s LIDDA Service Coordinator who is leaving and the Service Coordinator who is taking over, and the MDS nurse, and reviewed available records. MM and her sister speak primarily Spanish so I used a telephonic Spanish/English interpreter during the in-person meeting

MM is a 79-year-old Hispanic woman, who has been residing at the NF where we met with her for a little over one year (admitted April 2016). Prior to that, she was in a facility in Brownsville, Texas for over fifteen years. This appears to have been an Intermediate Care Facility for Individuals with Intellectual Disability even though the PASRR Level 1 completed by the nursing facility refers to it as a “group home”. Before that facility, MM lived at home with her family. She was recently assessed as having severe ID and formerly as having moderate ID. Other diagnoses include Type 2 diabetes mellitus, cataracts, hyperlipidemia, hypertension and unspecified glaucoma. She has limited functional communication. She walked with a walker until recently and has what appear to be congenital birth defects that caused club foot and left-side weakness.

MM is a very sweet and warm person, who smiles a lot when she is feeling well. She can be humorous, doing things like playing air guitar. She clearly enjoys when she gets others to smile (when she is in a good mood as she was when I met with her). MM is very close with her sister, who acts as an LAR, and supports her and advocates for her, although MM’s sister was not yet her legal guardian as of the time of our meeting. MM’s sister expressed how it is increasingly difficult for her to have MM to her home for visits, due to her own health issues. Unfortunately, MM has shown some decline in terms of her energy and interest in activities recently, and possibly her strength. Since MM moved into the nursing facility, she has fallen several times, begun using a wheelchair, had an upper respiratory infection that reduced her strength, and has developed hand contractures. Her sister has been concerned about the progression of her contractures and her use of the wheelchair. A nursing note indicated that MM’s sister stopped by the nursing station to share her view that her sister did not need and should not be in a wheelchair. I concur that MM should have had an updated assessment and more aggressive physical therapy to try to prevent loss of skills and independence.

MM has not received a comprehensive functional assessment of all habilitative areas that accurately identified all of her strengths and needs. Her May 6, 2016 PASRR Level II Evaluation identified only 3 needs (ADLs, medications, and nutrition) and Service Coordination was the only recommended PASRR specialized service, despite her various challenges. Though she had the usual nursing facility assessments, there is no evidence that MM ever received an examination of multiple domains, to include social skills areas, affective areas, community living skills, or behavioral needs – all areas that can impact the need for services to support the individual to function as independently as possible. When asked, the MDS nurse commented that physical/occupational therapy and speech evaluations are done on admission only “if they are needed.” However, it is difficult to know what is needed without an assessment; the lack of assessment is likely the reason that MM has not received the specialized services that she needs. In my experience, a comprehensive ISP must be informed by assessments that include a wide range of areas. It was documented that MM will shout “No” and “Shut up” at the Service Coordinator (SC) when the SC visits her and that she is easily agitated (though easily calmed), has low motivation for socialization, and has had difficulty expressing herself. Yet there is no record of timely assessment for emotional issues or social development, behavioral, and cognitive areas. Although, MM has difficulties with her speech and struggles to be understood and to ask for what she needs, she has not had a speech assessment recently to determine whether she could benefit from speech therapy. MM’s care plan included a goal for her to accept the judgment of staff, for example, but there was no associated assessment explaining why this was a goal. I also saw no assessments aimed at examining what MM’s needs might be for her to be out in her community, that might indicate she would benefit from LIDDA specialized services such as a day habilitation program or Independent Living Skills.

MM is not getting all of the necessary nursing facility and LIDDA specialized services, with the appropriate intensity, frequency, and duration, to address all need areas. Based upon my review, it does not appear that MM received habilitative OT and PT on a consistent basis even though consistent provision of habilitative OT and PT would be indicated given her ambulation challenges and her need for assistance with maintaining independence in her self-help skills. She has received OT and PT services including the following: MM’s May 10, 2016 Care Plan, one month into her stay at the current nursing facility, notes her contractures (osteoporosis and “muscle weakness”) as well as her congenital foot anomalies. PT and OT assessments were done in May of 2016 after her admission to the facility. MM received a short period of PT and OT sometime before July 2016. MM reportedly fell on August 20, 2016 but was not injured. Other notes from 2016 showed that her contractures were a concern and she fell in December 2016. MM again received rehabilitative OT from August 26th to October 7th of 2016 and was discharged because she “met her goals”.

The ISP/SPT meeting on January 5, 2017 noted that MM’s toes were curling in and that she had a recent fall, but the records do not indicate that she was getting PT at the time, and habilitative OT was declined because she was in rehabilitative OT at that time. At the January 5, 2017 meeting, the SC notes that MM was becoming more social and participating in some activities outside her room. It appears she did not receive PT until sometime in February 2017, but was dropped from PT again by the June SPT meeting. Her June 13, 2017 IDT had missing pages so I could not see what Specialized Services are currently recommended but it does seem she has received some OT and PT since then. Her PT note describing services between June 2nd and July 7th, 2017 indicated that she was receiving services for wheelchair management, independence in self-care, and other goals. Other notes indicate MM has a history of falling and fell on July 7, 2017 without injury. PASRR PT started again on August 29, 2017 and projected services through an October 12, 2017 target. OT was in place again as of June 20, 2017 with July goal dates and was also provided again in August with target dates through September 2017.

MM’s records indicate that a “decline” was seen as the only legitimate trigger to step up her physical or occupational therapy. The MDS nurse stated that, in general, habilitative OT and PT services can help to prevent a decline in functioning such as when OT is used to prevent or slow the progression of contractures. For example, a December 30, 2016 Service Coordinator note also noted she had a fall “last week.” The Service Coordinator asked one of the Nursing Facility staff about any changes, progress etc. and it was reported that she was walking “just fine” and they did not know how she fell. The Service Coordinator asked if there was any “decline.” The response was that MM was “Continuing to walk just fine.” She had just finished “all 3 therapies in July” and now will put in for OT evaluation of her hands and “Restorative” services. Her sister conveyed that she worried that MM’s hands “were getting a lot worse.” Despite these discussions, MM did not receive ongoing habilitative PASRR services to address her speech or walking problems. It was then agreed that OT services would be arranged due to her sister's worries about worsening contractures. The Service Coordinator instructed the nursing facility to "run it through NF first" and, if not approved, then they could consider PASRR. The NF staff were the ones actually asking about PASRR services at this time. MM likely declined in these areas over the years of nursing facility living, during which time it appears that at best, MM sporadically got some of these services.

There had been recent discussion of getting a CMWC for MM. This discussion came up when MM was weaker and not feeling well due to her upper respiratory infection, and she began to use a wheelchair and not want to walk as much. This situation seemed to have evolved over a short period of time. Her sister recalled that MM's mobility and contractures worsened over time in the nursing facilities. Over the course of MM's stay at the current facility, notes suggest a decline in her functioning. This may have been mitigated through more interventions, such as consistent habilitative PT and OT.

One note in MM's Nursing Facility chart documented that her sister stopped by to state that she did not feel that MM needed to be in a wheelchair. According to her records, it was subsequently decided not to pursue the customized manual wheelchair, but instead to focus on helping her get stronger and continue to walk with a walker. There was a limited view by the NF staff of what can be done with PASRR to help someone in terms of preventing further decline (i.e. contractures). But here, even when MM was demonstrating a decline, her staff rapidly decided to put her in a wheelchair instead of helping her walk again with a walker - using a more restrictive manner of managing her physical difficulty.

MM had ST through Medicare Part B but it was discontinued as of June 30, 2016. There is no evidence that she received any further ST. She would have benefitted from PASRR ST and her sister wanted her to have this. When asked about ST in our meeting, given MM's challenges with eating and making herself understood, the Service Coordinator stated that they had not discussed ST in the last SPT, but agreed they should add a speech assessment at the next meeting. MM would also have benefitted from Independent Living Skills services, attending a day habilitation program, and possibly behavioral support services. These services would help her learn and maintain skills for independent living, which is important to her, and to transition to community living. MM's sister agreed it would be helpful if there was a person who could transport and assist MM to visit her, which should be available as part of Independent Living Skills services.

MM is not receiving a continuous program of active treatment that is consistently implemented. The necessary specialized services she needed were not part of a continuous active treatment program. MM could have benefitted from multiple SS as noted above. The services though provided at times, did not include aggressive, consistent implementation of a program of specialized treatment and related services clearly directed toward acquisition of the behaviors necessary for her to function with as much self-determination and independence as possible. To be considered as meeting this standard, a treatment program must address prevention or deceleration of regression or loss of current optimal functional status, as well as skill acquisition. As noted throughout this report, MM's services were either intermittent or absent.

MM has not had a professionally-appropriate ISP that was developed based upon a comprehensive, person-centered assessment and that includes all needed services and supports to successfully transition to the community. She did not have all of the appropriate assessments, as described above. Her ISP did not include service recommendations I believe would have been important, including ones to increase her independence in communicating by having ST and to be getting experiences in the community. Her ISP and other records also do not include any evidence that there was individualized transition planning to determine which services MM would need and could receive if she were to transition to the community.

MM would benefit in multiple ways from living in in an integrated setting with appropriate community services and supports, and could have benefitted from these services years ago. If MM had an integrated setting with the appropriate community services and supports, she might be able to live closer to her sister and attend community activities, such as church and music events that she enjoys. She could access other activities that she might be more interested in and would have more opportunities for socialization, because such placements and services can be individually developed for her, based on her individual preferences, in a community setting.

MM and her sister have not made an informed and meaningful choice for MM to remain in the nursing facility, though the choice to remain in the NF was documented and pamphlets were given out and there was some discussion. MM and her sister did not appear to fully understand the benefits of community living. It was clear that more efforts are needed to insure that they really understood the individually-designed services that could be available to MM in a community placement I do not believe MM is fully capable of understanding the Community Living Options presentation, and she could not make an informed decision. Her sister seemed unaware of what was in fact possible in terms of the type of care MM might have in a community setting. Her now departing Service Coordinator reported she had provided MM's sister with a list and pamphlets that explained the options. She described having told MM's sister that there are staff supports and even nursing available in the community residential and program settings, including day habilitation programs and all the same services available in the nursing facility, which is an important step. It did not seem that this was clear to MM's sister, who saw anything community-based as incapable of providing care to her sister. MM had little to no experience with what type of care is available in a community setting, since she has never had service through the system of care for people with developmental disabilities.

MM's departing Service Coordinator had been working with her since February 2017, and there were two previous service coordinators, with her current service coordinator orienting to her job now, suggesting extensive turnover. It seemed there may have been limited opportunities for developing a relationship with MM and her family to the extent that might support more in depth discussions regarding the nature of options. It would be important to engender some trust in the availability of an individualized and safe and effective person centered plan to support someone in a community setting who has disabilities such as those experienced by MM. The service coordinators also did not appear to have details about the reasons MM entered the nursing facility or about her past residential placement experiences

I discussed community services with MM's sister. She confirmed that MM's LIDDA Service Coordinator told her about community options and other services that could be available to her sister. MM's sister stated that she did not think a community placement would work for MM because MM needs a lot of help and cannot do many things for herself. Although MM's sister expressed that she had chosen for MM to remain in the nursing facility, there was little evidence that the Service Coordinator had attempted to identify and address barriers or the reasons for this decision. Due to the lack of LIDDA specialized services, MM has not had experiences to work towards or experience a community living situation. MM's sister seemed open to considering touring either a community placement or a day habilitation program (but would need more reassurances). I believe she would consider these options if helped through a trusting relationship with a service coordinator and with more concrete means of showing her what a life in the community might be like for her sister such as showing a video or linking her to other families who have had positive placement experiences. MM does not need to be living in a restrictive setting such as a nursing facility, and she could live more independently and happily in her community.

CE

Date of Visit: September 7, 2017

I spoke with CE's Service coordinator, a LIDDA manager, her sister (guardian/LAR), her brother-in-law, one of her regular nurses, the Occupational Therapist, and her MDS coordinator nurse.

CE is a 71-year-old woman who had been living with her sister and brother-in-law until November 2016, when her family decided they could no longer manage her care. She has been at the nursing facility where I met with her and her family since then. Prior to entering the nursing facility, she had always resided with family members: for years with her parents and later her sister and brother-in-law. She has a history of "neuroendocrine cancer" and was in remission from her cancer since 2009, but became ill recently and her cancer spread to her liver. Her family members did not consider a community living option for her because they had never experienced these kinds of settings and did not appear to be aware that they could be appropriate for her needs. CE had never been in any kind of developmental disabilities system of care services (not even outreach, day programming, or service coordination). CE's family members assumed that their loved one needed medical care, and searched for a nursing facility for her. CE is a very sweet but also apparently very vivacious and strong willed person. CE reportedly generally keeps to herself, but occasionally, she shows her fun side and will dance to music she likes. When with family, she brightens up a lot. She always enjoyed food and music. She is very engaged when her family is present. Her sister and brother-in-law visit her often and watch over her care carefully. They have been fierce advocates for her. They began taking her with them into community activities such as going out to eat and to church after she moved in with them when her mother died, and they found that she thrived as a result. CE now tells them "I want to go to town!" She enjoys a number of activities when out and about, but especially anything that seems like a party.

I do not see evidence that CE received a comprehensive functional assessment of all habilitative areas that accurately identifies all of her strengths and needs. There were some limited assessments, and these reflect the type of assessment most anyone in a nursing facility might receive (such as the MDS). Her initial PASRR recommendations for Specialized Services on November 22, 2016, were for ILST, Service Coordination, and Alternative Placement Services. No PASRR Nursing Facility services were recommended. An Interdisciplinary Plan Review from the NF records dated May 30, 2017, just mentions a few of her medical issues. This document lacked any discussion of her individualized outcomes and there is no reference at all to specialized services (either recommended or rejected). Much of the focus was on her nursing care, yet when she first came to the facility, and until recently, she did not seem to be in need of much skilled nursing care at all. There was no assessment provided regarding her communication needs (no Speech Evaluation). She had some initial PT and OT evaluations at the time of her admission. Other areas in which an assessment should have been conducted would include a review of her self-help development; sensorimotor development; affective development; auditory functioning; cognitive development; social development; adaptive behaviors and independent living skills.

I do not believe that CE was receiving all necessary nursing facility and LIDDA specialized services with the appropriate intensity, frequency, and duration to address all of her areas of service needs. Service coordinator notes confirmed that she did not receive any specialized services except for service coordination. I did review an SPT meeting summary dated 5-30-17. This form had boxes checked to indicate that CE had no Specialized Services, and then that she was satisfied with her Specialized Services. She was getting only Service Coordination at the time. Her family members requested speech services and the SPT documented that they would seek a screening for Medicare funded Speech services and only if needed would they look into PASRR speech and language services. CE's family wanted CE to have speech therapy, and it was unclear why this was not an option for her. They had hoped this might help increase her communication as she tends to not speak out, including not being able to reliably tell others if she doesn't feel well or needs help. I believe an assessment at least should have been conducted to assess her potential to benefit from speech services.

She had some limited physical therapy, but only through Medicare (documentation shows she had PT through Medicare Part B between Nov-Dec 2016). She transitioned into "restorative" services (where staff trained by the physical therapist execute services) after having PT that was through Medicare and short term. I could not find evidence of any further skilled PT or OT services despite references in her Care Plan to her needing assistance and being at risk of loss of independence in ADLs and also risk of falling. A note written by the SC documented PT as being discontinued and restorative services starting 12/5/16. She did not receive habilitative PT or OT services that I could find anywhere in the documentation. She appears to have had needs that could have been addressed by providing these services that would promote greater independence and help her retain skills for as long as possible. One of the Rehabilitation staff stated that ST is only possible when a person displays a decline in functioning. Care plans described her as not communicating well, but somehow, it seems if she did receive ST it was limited (I saw no notes). There is a notation by SC in her monthly follow ups that ST was going to occur 12-20-16 for 30 days. Her Care Plan with an update in September 2017 still listed her as having difficulty making herself understood. A June 2017 Quarterly SPT note did document that the team would meet and recommend SS of ST, so it is unclear what she did in fact receive for these services. As of 5-30-17 SPT meeting, she was not receiving any NF SS.

Some of the lack of pursuit of nursing facility specialized services may be due to a lack of understanding of PASRR on the part of both the NF staff and the LIDDA staff. For example, a NF occupational therapist told me that the first she ever heard of PASRR was "yesterday." Another example of this lack of understanding is that her MDS nurse stated to me that her understanding was that, if a person was "headed to the community," they would get PASRR services to "get ready for it." She defined "habilitative" care as being all about "getting out into the community." She did not believe PASRR services could be provided unless you go through OT and PT Medicare funded options first. She further stated that speech therapy can only be provided if the patient has a decline in functioning.

CE was not provided with independent living skills training or services, and seems to get out into her community most often when her family takes her. She loves going to "town," out to eat, and to musical events. Independent Living Skills services were not provided and she did not attend a day program. She may have had much more access to these things she loves to do through PASRR supported such LIDDA specialized services. However, CE's family members expressed concern that CE needed to first adjust to the new people at the NF before trying ILST (this would have provided someone to take her out into the community). This was despite her fairly smooth acceptance of staff who were strangers at the nursing facility. Also, CE was described as preferring to be in her room and only at times joining activities, while she always became animated about going out of the facility into the community.

Nursing staff agreed that she has had very limited nursing needs throughout her stay at the nursing facility. Her nursing staff did not know of her needing any rehabilitative services, described her as having no significant concerns, and noted that CE was able to engage in activities she chose to attend. She apparently doesn't like the crowded areas much and may avoid them. Her nurse noted only a mild adjustment to moving into the nursing facility, when she at times would state she missed her sister. Based on this, it would seem she could have attended a day program or been going out into her community if PASRR specialized services were in place, and, alternatively that she could have gone from her family home into a community option instead of entering the nursing facility in the first place.

I do not believe CE was receiving an active treatment program directed toward skill acquisition and aimed at skills necessary for her to function with as much self-determination and independence as possible. As noted above, she did not receive a comprehensive functional assessment, which means her needs for active treatment were not identified. Furthermore, she has not received the specialized services she requires for active treatment. For example, she was not getting speech services to help her be more able to express herself, even though this was requested by family, and would enhance her capacity to express her wishes and needs, and be more independent. She was not having regular community programming or outings to build or maintain such skills so she cannot have been receiving services at an intensity and frequency level to support desired outcomes. Also, plans for the delivery of specific services are derived from a comprehensive set of assessments, which as noted, was not conducted in this case. She was not receiving services that would promote independence and prevent regression. Also, the staff at the nursing facility did not appear to have been trained to work and treat individuals with IDD, which would impact the quality of the treatment. Unfortunately CE's cancer relapsed, resulting in a potential move to hospice. Her nurse mentioned she knew of people in Hospice for as long as 2 years, though prognosis for CE was unclear. It is concerning that hospice would mean even less potential for being active and work to maintain skills or prevent decline based on the individuals unique clinical presentation rather than this type of rule. CE was still asking to and going out to "town" and with family when I met her, despite her illness.

I am not able to verify whether or not CE has a professionally-appropriate Individual Service Plan that was developed based upon a comprehensive, person-centered assessment and that includes all needed services and supports to successfully transition to the community, because the one provided is missing every other page. I did not see anywhere documented what she might need for supports and services if she were to move into the community and it looks as if this section of the ISP on page 9 (where what she would need to be assisted to reside in the community) is blank. I cannot determine if the nursing care plan and ISP goals and services are integrated as the missing elements included goals and specialized services that would be incorporated into the ISP goals. It was noted that she had to be placed on a "secure unit" because of her history of wandering. It should be noted that many people with IDD would wander off if they did not have meaningful engagement in active treatment with services addressing their interests and preferences, and without staff interacting and supervising the person. The response that instead, in CE's case, she is put in a secure area reflects how institutions tend to respond to these challenges very differently and in a more restrictive manner than occurs in community settings.
CE would definitely have benefitted from living in an integrated setting with appropriate community services and supports when she first moved out of her family home, and would still have benefitted even as of my meeting with her. I believe she did not get to have this opportunity because her family members were never fully informed and shown that community options can support people with IDD who might wander, which was their primary concern, and who need someone to give them their medications and help structure their day. None of her needs were such that she could not be served in a community setting. In such a setting, I believe she would have access to more community activities that she enjoys. She also could have been perfectly safe in a community setting.

I do not believe CE's family/LAR were able to make a fully informed choice to have CE remain in a segregated nursing facility for a few reasons. They are wonderful advocates but seemed unfamiliar with details of potentially available options. CE's service coordinator has been working with her only over a brief time that she has become known to the IDD system of care. She reported that she told the family that there are community living options, but that CE's family declined such options. CE's brother-in- law and sister reported that they initially had examined a group home as a possibility, but remained concerned that CE wanders, needs help taking her medication and needs careful supervision. They did not believe community options could be safe and manage these concerns. Telling them that group homes do provide care that includes the things that worried them was insufficient to allay their fears and address the barriers to community living. These services are actually standard services and interventions group homes implement all the time.

It would seem important to build trust over time with family members who express concerns that may not be necessary, and to address such barriers through use of varied strategies to inform them fully of the real options available. For example, service coordinators could possibly arrange for a worried family to speak to another family member who had success in helping their loved one move successfully into a community setting and to describe the benefits in improved quality of life over and above usual living circumstances in more restrictive settings. Other possibilities could include things like use of short videos, meeting providers, having a "social" event with providers and other service users or other means to acquaint them more with actual safe and positive options. I did not find any evidence that this family was provided with these kinds of opportunities. Further, it would be even more critical for individuals like CE that aggressive work be done to avoid facility placements in the first place. I am unaware of the exact efforts made to do so in this case, but have found minimal documentation explaining why someone with so few needs for facility care ended up in this type of setting.

RS

Date of Visit: August 25, 2017

I interviewed RS, her brother who is her guardian, an administrator, an MDS nurse, and a social worker from the nursing facility where she lives, and reviewed available records.

RS is an approximately 87 year-old woman who has an Intellectual Disability, hearing loss and who needs a walker for ambulation. Her brother told me that no one actually knows her age because of their rural roots. RS lived for years with family, and moved to the current nursing facility in 2011. Before this, she was in a facility in Oklahoma where she moved from her brother's home, as he was feeling unable to care for her in his home as he aged. He was unhappy with the care she received at the NF in Oklahoma, and decided to move back to Texas (where other family resides and where they had originally come from). RS came with him, and was placed in the NF where she currently resides. RS has history of Rheumatic fever at an early age, at which time "her ear drums were ruined," according to her brother. She has had hearing aids, but frequently loses or breaks them. When I spoke with her, her significant hearing problems were notable. She was born on a farm, one of ten children. She apparently received a 3rd grade education. However, there were no special classes or services offered to her when she was a child. She stayed with her mother for many years, and then lived with her brother and sister-in-law. RS has a great sense of humor and seems very close with her brother, as they joked and laughed together a lot during our interview.

RS' room at the NF is covered with many lovely family photos. She loves doing exercises (3 times weekly), playing BINGO and socializing. She greatly enjoys having a daily job, which is setting the dining tables. Her "duty" every day is to set out napkins. She used to give out water but is no longer physically able to do this. Her brother feels that this task is good for RS, as it makes her feel needed. Her brother takes her out every Sunday to see family. She apparently greatly enjoys going on this outing. RS also loves arts and crafts and crossword puzzles. However, according to her brother, she spends a lot of time alone in her room doing these activities (and sitting for long spells). RS had been having problems walking and fell a few weeks prior to my visit, by her brother's report. It was then found that she had a blood clot in her leg, which needed to be dissolved. Her brother stated that he was worried about RS' lack of activity, and wondered whether it has contributed to the development of this clot.

RS did not have a comprehensive functional assessment of all habilitative areas that accurately identified her unique strengths and needs. Like others whose records I reviewed, she had usual nursing facility assessments (MDS, daily nursing care needs, medical needs), but not the scope and type of functional and other assessments that are standard practice for people served in the IDD system of care who live in community settings. For example, in the documents I reviewed, I did not find any assessments addressing independent living skills or challenges to her social skills/ development. Independent living skills and social development assessments would be especially important because she clearly wishes to be independent and to have purpose in her life and she has some issues in terms of her interactions with others. She had an assessment that addressed her difficulties communicating followed by 4 weeks of therapy covering the period between March 11, 2016 and April 22, 2016. This was a Medicare funded service and not a PASRR funded service. The same document noted previous ST occurred in 2013 (from October 10 to November 9, 2013).

Her PASRR Evaluation dated August 22, 2013 documented that RS needs extensive support for things like dressing and transitions from sitting to standing, selecting activities and making decisions, her social development, and community related daily activities. LIDDA Services recommended included Alternate Placement Services, Determination of Intellectual Disability and Vocational Training. Page 7, item B0600 regarding recommended services provided by the nursing facility is left blank. The same PASRR form cited above also documented that her brother/LAR was satisfied with the services provided at the nursing facility and that he did not request any additional services or changes. Section F page 21 of this form indicates that RS is not expected to return to the community, and that the LAR was given information about alternatives to facility living and other services, and declined these services. The PE is not an adequate assessment in and of itself, and includes only a number of check boxes that would reflect the findings from more comprehensive assessments. For example, usual assessments of independent living skills describe in detail what the individual can and cannot do and what types of help will be required such as whether or not a person can make change or needs help to purchase things, or budget or what the person understands about dates and days of the week (and other time concepts).

Though some of her interests and preferences were noted in her records, it was not documented or planned how to include these in her life in a way that also promoted her independence, but did not contribute to her being isolated. She may need a functional behavioral assessment and positive behavior support plan to help her to be more independent, by reinforcing use of her hearing aids that she has not been using (due to losing them or breaking them). Her inability to hear what is being said around her may contribute to social isolation. Key assessments are also missing to determine what might be helpful to prepare her for a transition to community living or to support her being as independent as possible.

RS was not receiving all necessary PASRR LIDDA and Nursing Facility specialized services with the appropriate intensity, frequency, and duration, to address all need areas. As noted above, the assessments done were insufficient in identifying what PASRR services would have benefited RS. The PASRR form, dated October 4, 2013, was incomplete. Her brother's contact info was written on the form, indicating that his role as an LAR was known. RS' brother reported "I never received anything from the state." He was quite certain he had not been approached about Specialized Services or community living options. He stated he would be interested in hearing more and noted that RS needs to be active. He confirmed that he would be very interested in services that would help RS. He noted he would also consider community living options, as long as her basic needs would be provided for (such as assistance being active, with medication, with ADLs, and with transportation to appointments). It appears at least that the LIDDA did not have anyone discuss options with him any time recently; this is unfortunate as he indicated his interest in these services. The social worker and nursing facility administrator also noted that one of RS' sisters had refused services. However, they were aware that her brother is the legal guardian. He had never been offered these services by his report, and therefore could not have made an informed decision about them. The nursing facility staff I spoke with were also unaware that RS had a problem with falling or had developed a blood clot. Based on my review, RS has likely suffered harm as a result of the extended period of time without specialized services.

RS would benefit from numerous specialized services, including: speech therapy to assist her to better communicate (ongoing and habilitative); OT services to help her maintain as much independence as possible in her ADLs; PT to prevent decline in her mobility and prevent further falls; day habilitation programming where she could be more active and find more activities to provide her with purpose; independent living skills, and possibly behavioral services.

The nursing facility specialized services she has received have been intermittent and provided for limited durations, mainly after a decline or an acute incident. A PT note from May 2015 documented that she fell and was for this reason being seen by the PT. The PT stated she had a mood disorder which is not documented elsewhere aside from an OT plan of care. It was noted that she ambulated independently around the facility with her rolling walker and that she had last been discharged from PT services in March 2015. It would seem likely that since the service was aimed at building her strength and balance to prevent falling, that suspending services and not providing habilitative services in a consistent manner may have contributed to her falling. As a result of the fall, it appears she received PT from May 18 to June 16, 2015. The service was provided through Medicare Part B. Next, documentation provided listed PT as starting again from December 15, 2015 to February 12, 2016, then from March 11 to May 10, 2016 stating she had been hospitalized due to cellulitis (serious infection) and that she needed PT again because this had caused weakening of her strength. Services then were not documented again until October 7 to November 5, 2016, and then not again until May 9, 2017. OT was similarly provided through Medicare and when she was seen as in decline such as after her hospitalization in the spring of 2016. She was also getting OT more recently with goals set for completion in August 2017. RS has received some speech therapy, first from March 11 to May 9, 2016, following a fall, and again starting in April 14, 2017, following a decline in alertness and participation in activities. As discussed above, RS received about a month of ST in 2013 and again in 2016. It appears she began receiving ST again through Medicare on August 15, 2017.

RS did not have a record of receiving any LIDDA specialized services. RS has received some speech therapy, first from March 11 to May 9, 2016, following a fall, and again starting in April 14, 2017, following a decline in alertness and participation in activities.

RS is not receiving active treatment. This is clear based on the above information since she did not have comprehensive assessments that could inform an appropriate ISP that had goals set based on her strengths, preferences, and needs, and an outline of services and interventions needed to meet these goals. She is not receiving ongoing, habilitative treatment to promote her independence, to maintain her skills and functioning and to allow her to function with as much self-determination as possible, especially given no one is addressing the problem with her behaviors related to use of her hearing aids (which might be resolved using approaches such as positive behavior shaping). She may like certain NF activities, but is described as spending a lot of time alone in her room, and being sedentary to the extent that her brother worried about her blood clot being related to this. Her lack of ongoing habilitative PASRR OT and PT likely has contributed to her functional decline and especially falling.

RS does not have a professionally-appropriate ISP that was developed based on a comprehensive, person-centered assessment that includes all needed services and supports to successfully transition to the community. There was no comprehensive ISP completed and RS was not provided with individualized transition planning. Furthermore, as noted above, there were insufficient assessments completed to inform the development of a plan to address RS' strengths, weaknesses, needs and related goals, nor is there any means to measure progress towards goals that would address all of the areas noted above. I saw no documentation indicating there had ever been a discussion regarding transitioning to the community, or identifying potential barriers to community living.

I believe that RS would benefit from living in an integrated setting with appropriate community services and supports. She could be adequately and safely served in the community. RS previously lived with family happily. She moved to a nursing facility because her aging family was unable to care for her. The family was not aware of all of the settings and supports available in the community and therefore did not make an informed decision for RS to be institutionalized in a nursing facility. If she were residing in a community setting, she could be making friends, socializing, attending a program, and be active and involved in her community. At a day program, she could be able to enjoy the activities she likes now, but would not be confined to doing these activities alone in her room. Continued institutionalization in a nursing facility is neither necessary, nor appropriate for RS.

An informed decision was not made for RS to remain in a nursing facility. She and her LAR, her brother, were not presented with options, contrary to what is required for PASRR positive individuals. The nursing facility staff reported that RS' sister stated that she did not want any CLO or other specialized services for RS. This is difficult to understand, since her brother was very clear about being open to hearing more about options that could improve the quality of RS's life. The nursing facility staff were adamant that RS had no need of any specialized nursing facility services, and that her family did not want LIDDA services or CLO. The LIDDA staff did not attend the interview. The documentation provided did not include a description of barriers for community living specific to RS and then how one might address these barriers nor was there any detailed description of what an effective set of services or life in the community would look like for her, that could best meet her needs and be responsive to her interests and preferences. Sadly, it may have been some time since anyone has even attempted to present options to anyone in her family, including and especially to her and to her LAR.

JG

Date of Visit: August 24, 2017

I reviewed the records provided to me. I also met with JG and his nursing staff at his nursing facility. Efforts were made to reach LIDDA staff but they did not return calls.

JG is a 62-year-old man who acquired polio (poliomyolytis) as a child, and also had mumps. He was admitted to the current facility on March 26, 2014. He was unable to say where he lived before this or how he came to reside in a nursing facility. He did say that he was in a different nursing facility before the present one, and that it was a bad experience. He talked about growing up on a farm. He needs a wheelchair now because he has paraplegia. He explained that he walked with braces as a child but gradually his condition declined and his movement was increasingly affected. He has a variety of other medical and mental health diagnoses including Gastro-Esophageal Reflux Disease, constipation, Schizoaffective Disorder, Major Depressive Disorder, psychosis, Hepatitis C, hyperlipidemia, inflammatory liver disease, Hypo-osmolality, hyponatremia, unspecified kidney disease, Crohn's disease, and obesity. He takes many medications. My initial impression of JG was that he seemed sad and anxious. JG told me he used to read the bible, and do other things such as going on rides into the community, but that he now lacks interest in much of anything. He eventually shared that he likes to watch "Ultimate Fighting" and sometimes wrestling. He seemed hopeless that he could feel or function better, or that anything might be available to him so that he could have hope. He shared that he is sad that family members do not want to be involved with him, and that he tried calling his son and that his son hung up on him. He is religious, stating, "I hope I will be forgiven for what I do" also that, "I wish my son would forgive me." Before we left, he asked us to pray for him.

JG has not received a comprehensive functional assessment of all habilitative areas that accurately identifies individual's strengths, preferences, and needs, and I believe he has suffered because of this. He seems unhappy in his current situation and would benefit from a comprehensive functional assessment that would evaluate and determine his needs and the services from which he could benefit. JG refused to have a service coordinator. As discussed further below, I believe this refusal stemmed from his fears and lack of understanding of service coordination services. He did not have an IDT or ISP meeting, nor were there any assessments regarding his areas of need from the LIDDA. He had typical Nursing Facility assessments, such as ones done by his physicians, the MDS, and he has a nursing care plan. I saw no documents providing details regarding his self-help development, yet he seems to want to be as self-sufficient as possible. I saw no documents addressing cognitive issues (to see if he did really understand what was presented to him for services), independent living skills, social development (he is very isolated). Even if he was to refuse services, he was never assessed to determine what might be helpful. This is unfortunate as he would benefit from specialized services to address his needs and his social isolation. Specifically, JG would benefit from assessment and interventions in numerous PASRR supported areas including: OT, PT, Behavioral Services, ILST, and more importantly, he would benefit from a move to a supported living situation in the community. In a PASRR Evaluation ("PE") dated April 10, 2015, the evaluator determined that JG was PASRR-eligible on the basis of developmental disability. The Qualified Intellectual Disabilities Professional (QIDP) who assessed JG did so only for IDD and then only recommended Service Coordination, despite JG's clear challenges with movement and mobility, and his desire for independence. No specialized nursing facility services were identified as potentially helpful. On Page 28 of the PE, the evaluator identified JG's barriers to returning to the community to include a lack of family support available, limited accessible housing, and that his care needs are likely greater than the support available in the community. On Page 29, which should contain a list addressing what is needed to support JG in the community, was blank. However, an SPT meeting occurred after my visit and a note from the LIDDA Social Worker dated August 31, 2017 stated that JG needed someone to help him explore options (because of his fears that accepting services would lead to his "dismissal"). This was positive to see, and the team provided him with reassurances that he would not be dismissed, and that they had found someone willing to help him and to become his guardian. He was at first skeptical but agreed to having PASRR services specifically because it would include his being able to get a CMWC.

Based on my review, JG's refusals of specialized and other services have not been informed. JG appeared extremely fearful of being homeless. He was concerned he might be sent to live in a shelter, or have nowhere to live. He did not seem to understand that he was being presented options for additional services and supports or for community living with supports, or that he would not be penalized for considering these. At the time of my visit, it was clear to me that he needed an advocate to work with him to understand his options for care and support, even though at the time he did not have this support and had simply been going without any PASRR services for years. The documentation in JG's records suggest that he needs help to make decisions. The MDS dated March 9, 2017 notes cognitive loss/dementia. On page 11/12, it was stated "no" to does the resident reject evaluation or care and symptoms of depression were rated higher for this MDS than in prior ones. It was further noted that JG was unable to report the correct year, and needed help to report the month and correct day. For 3 word recall, he needed cuing for two and could not recall the third at all. All of these assessments suggest that JG needs help to make decisions, yet he did not receive this assistance.

At the time of my visit with him, JG was not receiving any PASRR NF or LIDDA services from which he could benefit. A March 9, 2017 Care Plan note documented findings related to cognitive impairment, and stated he prefers to watch TV in his room or people watch (he rarely joins activities). He "feels bad," is tired, and has low energy. I believe he would benefit from specialized services of OT and PT to help him maintain his strength and independence to the greatest extent possible. I believe he would benefit from behavioral services and ILST services to help him get out into the community and to prepare him for community living. He might greatly benefit from getting involved with a church. He needs transportation and help to understand he would be safe and not be "put on the streets," as noted. He might enjoy a day program if there would be peers for him (others with a similar cognitive profile).

At the time of my visit, JG was not receiving active treatment, as he was receiving only daily nursing care and no specialized services. He appears to spend much of his time sitting in his room in his wheel chair except for meal times and occasionally joining an activity. During my visit, JG had difficulty naming anything he would look forward to. He did say he enjoyed watching "fights" (Pay-Per-View) as noted above, but seemed worried, sad and isolated. JG also appeared to be experiencing some physical decline and has experienced an increase in falling. However, JG does not receive PASRR rehabilitative services to help to slow the decline in function. JG also described falling out of bed because he had not lowered the bed to transfer from bed to wheel chair. Specialized services such as OT and PT, could possibly help him maintain or gain strength he needs to do transfers safely. JG expressed extreme sadness and frustration related to losses of independence and function.

During my visit, I interviewed one of the nursing staff who works with JG at his nursing facility. He told me that he felt that JG could benefit from specialized services and stated they (various NF staff) have tried explaining this to him. JG seems to be a proud person, and frightened about his fate. He is also hopeless that specialized services would make any difference. He stated in regards to therapy: "I don't want to walk because I don't want to fall." He is religious, and it seems like there is no one helping him pursue any of the things he cares most about. If he had a day program to attend during the day or a staff person who could provide him with independent living skills support and training, he could be assisted to pursue his interests and work to be more independent. JG described how he used to be able to go out when there was a driver who could manage assisting him moving to and from the van when he was out in the community. He seemed sad explaining that he feels he cannot go out anymore because that driver left and the new one cannot provide the assistance he needs.

As described above, JG does not have a professionally-appropriate ISP that was developed based upon a comprehensive, person-centered assessment of his interests, strengths, needs, preferences, concerns, and barriers regarding community living and especially one that includes all needed services and supports that might assist him to successfully transition to the community. An ISP should include the comprehensive assessment as well as goals for transition, a plan to enable the individual to make an informed choice about community living, and strategies to address any barriers to community living. There was very limited documentation of the barriers to JG's living in the community. In 2015, JG's Service Coordinator noted a lack of accessible housing, but did not describe how this problem could be addressed, or where he would want to live or how, if he was ever to decide to move. JG's nursing staff felt the greatest barrier was his own difficulty understanding what might be possible, and his own fearfulness and hopelessness. Due to his anxiety, JG dismisses people almost immediately, but he is likely to open-up, as he did with me if one is gentle, listens to him, and gives him the clear control over ending the conversation if he chooses. Rather than a single, short visit by his service coordinator, during which he is given "materials" about community living options, JG would need someone to first develop some rapport and trust with him to be able to discuss and learn what the barriers are to his living in a less restrictive setting. His Nursing Care Plan from March 9, 2017 stated that he declined all PASRR services, and goals were to "be happy" and "I will convey a sense of wellbeing in facility." It was noted that he sees a psychologist. A SC note from August 28, 2014 stated that he did not want any services, but provided no details. The duration logged for the visit was 15 minutes. There was a similar note from March of 2014.

I believe JG would benefit from living in a community setting if an individualize plan was developed to design a safe and appropriate placement for him. Continued institutionalization is neither necessary nor appropriate for JG. As noted, no one could describe exactly how JG came to be admitted to his NF. JG was quite vague about the circumstances leading to his admission to the NF. It was difficult for him to express a lot about interests. He seemed depressed and hopeless but indicated to me that he wishes he could reconnect with family.

I do not believe that JG made an informed decision to remain in the NF, and to live in such a restricted setting. A Community Living Options ("CLO") form dated October 9, 2016, documented that the service coordinator presented options (checked the first 3 of 4 boxes on this form.) However, there was minimal description of how the options were presented stating "materials" were provided, and the "individual did not want CLO or PASRR services." "He stated he is fine on his own and does not want to live anywhere other than the Nursing Facility." JG explained to me that he had received a visit from a Service Coordinator a while back and told her he needed to stay at the NF which might be confused with he *wanted* to stay at the NF. However, when I spoke to him, it was clear that he was afraid that the service coordinator was going to cause him to be homeless so in fact, he did not understand his actual options. JG was fearful that accepting help could result in being sent away. He was not provided with individualized information about community options that would have addressed his concerns, such as his concern of being homeless or his concern that he would not receive assistance. Since he had refused even service coordination, I suspect there was not any effort after the CLO discussion, to show him options by visiting places he might be able to live. If he was able to see for himself what his options could be, he may have been less fearful. Fear of the unknown is a common concern when deciding about a big change such as moving out of the NF; but is even more pronounced for this gentleman who has a history of expressing significant anxiety. It was noteworthy that after out visit, with some extra efforts, his team was able to get him to at least discuss accepting much needed help.

The October 9, 2016 CLO for JG and the section of the ISP that should include a description of what would be needed for an appropriate community placement for the individual is left blank, and is to be filled out after a person has made a decision to move out of a NF. (See 1041 detailed instructions). However, it is my professional opinion that in many cases, having this information discussed and documented and reviewed with the person would be important and extremely helpful so that the person would know what a life in the community would look like. He even told me that he was interested in having us help get him "out" and asked if we could do that. He seemed to want to remain at the Nursing Facility only because he did not believe there were other options, and was afraid of having toileting accidents in front of others, or being somewhere where there was not adequate support. He was unaware that people who are in a wheelchairs and require assistance with transfers and toileting can live in the community with support. It is hopeful that his IDT are pursuing a guardian for him and know to provide a lot of reassurances to help him see what kind of help he may access. However, it has now been several years or more that he has gone without the help that he could have received.

PO

Date of Visit: September 7, 2017

PO is a 58 year old male who has been living at the nursing facility where I met with him since August of 2016 Prior to admission to his current nursing facility, PO was living in a neighboring nursing facility, where according to his family and SPT, he became very ill and had to be hospitalized. Prior to residing at his previous nursing facility, PO resided at a group home. PO was unhappy there because his peers were not able to communicate as independently as he was. He reported that he did enjoy some aspects of that experience such as the access to community events.

I met with PO and his sister-in-law at PO's nursing facility. During our meeting, PO's sister-in-law described some of his history to me. She reported that PO was struck by a bus at the age of eight which resulted in him having had a stroke-like event that was associated with a traumatic brain injury with right sided paralysis. Prior to the accident, PO had developed normally. PO is diagnosed with moderate intellectual disabilities, general paresis and Major Depressive Disorder. He also was noted to have an enlarged prostate with urinary tract symptoms, blindness in his right eye and low in his vision left eye. He has a history of multiple stage 3 ulcerations. PO's sister-in-law is his main family member who attends meetings and advocates for him, though his two brothers apparently are quite involved as well. They reside locally so they are able to see him often.

PO enjoys making friends and is very social. PO would love to have the opportunity to go out into the community more often but his opportunities to do so have been limited due to the lack of availability of a van or other transportation that can accommodate his large wheel chair. The local LIDDA has just purchased a van so they can help with this. He continues to visit people at the facility next door where he resided previously, though this has been restricted at times because he fell out of his electric wheel chair trying to navigate the uneven terrain between the two facilities. He has a hobby in which he is extremely invested: he takes metal hangers and wraps colored yarn around them making them colorful. PO sells his hangers and enjoys this very much. We discussed how he could possibly parlay this into a real mini business in the community as well, with some support, since he already makes sales to staff and others at the facility. He has a long time habit of being a "night owl," staying up late working on his hangers and sleeping in the morning.

I did not find evidence that PO received a comprehensive functional assessment of all habilitative areas that accurately identifies all of his strengths and needs. Although, there was documentation showing that PO received some initial assessments including OT, ST and PT, I found no evidence that PO received comprehensive assessments done while at his nursing facility in some key areas such as regarding his self-help development; sensorimotor development; affective development; cognitive development; social development; adaptive behaviors and independent living skills; and vocational skills. I did not see any assessments that addressed specifically what kind of help he would need or what supports he needed in terms of seeking an alternative placement.

PO received a PASRR Level II evaluation, which was done on 10-17-16. Based on this evaluation, it was determined that he needs self-help with activities of daily living (ADLs) and assistance in regards to speech and language (communication development), with LIDDA recommended services of alternative placement services and service coordination. Nursing facility specialized services recommended specialized ST and specialized OT. Some assessments were done initially including OT, STs and PT.

PO has not received all the necessary nursing facility and LIDDA specialized services, with the appropriate intensity, frequency, and duration, to address all need areas. PO needs OT to address a variety of needs (i.e. to prevent further worsening of his upper extremity contracture and skin break down, to prevent decreased trunk control and decreased strength as well as decreased ability to participate in self-care and leisure tasks); and PT to prevent any further declines or loss of strength and to prevent problems with positioning in his wheel chair that in turn are associated with skin break downs. Despite these needs, he has not received these services consistently or with the intensity that he needs. Although PO was initially provided with some limited PT in the fall of 2016, funded through Medicare according to a monthly summary written by PO's physical therapist, PO's physical therapy was discontinued after 12-22-16 because PO was waiting for approval to receive PT through PASRR. Approval was finally granted on January 23, 2017. While a subsequent note states that he had one month of PT, it is unclear if he actually received specialized/habilitative PT based on the limited details/notes in the record. There was also no evidence showing that PO received specialized/habilitative OT. He did first get OT through Medicare. Then from August to September 2016, he got restorative OT. He got OT services again between September and October of 2016 through Medicare. He had OT services between November and December of 2016 through Medicare Part B. April to May 2017, OT services were provided again through Medicare. In the summary of his OT services that ended on 5-10-17, it was noted that he demonstrated increased right upper extremity contracture and skin break down, decreased trunk control and decreased strength in "upper extremity," decreased ability to participate in self-care and leisure tasks. Through all of these services, I could not find any evidence that he ever got OT through PASRR and it is unclear whether he received even very limited PASRR PT services, despite documentation of ongoing need (and in the case of OT, a decline). He is noted to be at risk for further decline in multiple areas. There was a notation on document from PT dated 1-21-17 that an initial assessment was done 12-22-16 and no service initiated "due to waiting for approval from PASRR."

PO needs specialized speech therapy to prevent further loss of function related to dysphagia and maintain his speech intelligibility and be certain his able to make clear basic communications regarding his needs and preferences. PO had speech services through Medicare in the fall of 2016 and the spring of 2017. It was unclear from the records if these services were ongoing or if any of these services were through PASRR. For example, Medicaid was the payor for speech services he received in December 2016, but the service period was only one month (between December 28, 2016 and January 26, 2017). It seemed there were breaks in services. In his December to January Speech services note, it was documented as aimed at restoration, and the clinical impressions were that he presents with deficits in swallowing and speech abilities. He is at risk for aspiration, dehydration, depression, weight loss among other concerns and risks suggesting he really should be having ongoing interventions through PASRR if not happening now. A NF/Quarterly Assessment Review meeting note dated January 12, 2017 indicated there were no NF SS occurring at this time.

Further compounding the lack of specialized services was the lack of sufficient understanding of specialized services on the part of the nursing facility staff who work with PO. For example, PO's Occupational Therapist while open and caring but new to the facility, explained she had not ever heard of the term "PASRR" until she came to this facility. In another example, the NF Quarterly/ISP meeting note dated 6-15-17 indicated that although his SC observed PO struggling to eat, the staff from the NF's Rehabilitation Department did not believe that additional therapy was indicated because "He just got done rehab…" and that PO is at his "highest level of independence and use of his arm." This statement reflected a lack of understanding by the NF Rehabilitation staff of the possibility of PASRR habilitative services in the areas of OT and Speech therapy.

The NF Rehab Director told me that the NF Rehab Staff had limited familiarity with serving people with IDD or the concept of providing habilitative OT, PT and ST to people with IDD such as PO. The NF Rehab director further stated that they are taught to examine for declines and the patients must make progress to be allowed to treat and bill through Medicare. She also stated that they have provided habilitatve services at times, but the NF wants them to use Medicare. She believed that it was difficult to get re-approvals for PASRR services. PO's service coordinator reported to me that although she pushes for use of PASRR/Medicaid as a mechanism for payment for NF specialized services, she often gets "push back" from the NF because they prefer to bill Medicare. This seems to result in such services only being provided when someone is in decline (which is the trigger for allowable billing under Medicare Part B), and the services are provided only intermittently. The latter occurs because the services are only reinstated again after the person shows decline rather than as a means of preventing decline -which is one of the critical roles PASRR services can play. Ironically, in some cases, the decline is provoked by the cessation of services like OT and PT. Dropping care and a lack of continuous and preventive care may cause the decline that then allows Medicare funded OT and PT.

PO is also not receiving all of the LIDDA specialized services that he needs. At the time of my visit, the only LIDDA specialized service that PO was receiving was service coordination. The LIDDA staff with whom I spoke (service coordinator and director) told me that they anticipate that PO will soon receive ILST services because the LIDDA is purchasing a van that can accommodate people like PO who use large electric wheel chairs, to provide him with transportation for ILS services. PO has otherwise had limited community access. He is someone who would enjoy activities in the community such as eating out and going to the movies. PO's service coordinator completely agreed that more community access would be very desirable for him and he has not had this. His power WC is a second hand one and is in disrepair though functional. His brother works on it to keep it functional. PO has fallen trying to motor next door, even with staff support, when he tries to visit friends who reside in this NF where he once lived. (One fall was documented in January of 2017). This was very distressing for him and since he then was restricted from visiting his friends unless someone could go with him. The assistance of an ILST staff might be of help for him to see his friends.

PO is not receiving a continuous program of active treatment that is consistently implemented. The necessary specialized services that his SPT members felt he needed were not part of a continuous active treatment program. The services though provided at times, did not include aggressive, consistent implementation of a program of specialized treatment and related services clearly directed toward acquisition of the behaviors necessary for PO to function with as much self-determination and independence as possible. To be considered as meeting this standard, a treatment program must address prevention or deceleration of regression or loss of current optimal functional status, as well as skill acquisition. PO could have benefitted from specialized services, as noted above that he either did not receive at all of the services that he needed (e.g., ILS due to lack of transportation) or he did not receive on a consistent basis.

I am uncertain as to whether PO has a professionally-appropriate ISP that was developed based upon a comprehensive, person-centered assessment and that includes all needed services and supports to successfully transition to the community. I am doubtful because he has not received a comprehensive set of assessments based on the documentation, but I saw no ISP in PO's records. ISP goals and plans are built upon the comprehensive assessments, so one cannot be complete without the other. I cannot determine if his nursing care plan is closely aligned with the ISP, since I also saw no nursing care plans in PO's records.

I believe that PO would benefit from living in in an integrated setting with appropriate community services and supports. When I interviewed her, PO's service coordinator stated that she also believed that PO would benefit from living in the community with the appropriate services and supports. He did not like that he had difficulty making friends because his peers did not communicate as well as he was able when he tried this before. A new community placement would need to be designed to support PO in making friends and being able to communicate with his peers, including, ensuring that he has roommates or access to people with whom he shares interests and abilities so that he can make new friends. He would need transportation so he could continue to visit his old friends. He would benefit from having a life in his community, given how social he is and his enjoyment expressed in regards to outings now, which have been limited as noted above. I did not find an ISP where there could have been a transition plan described for him. Even though he has some significant medical issues, I do not believe he needs to remain in an institutional setting.

PO and his sister-in-law have not made an informed choice for PO to remain in a segregated nursing facility. I could not find a CLO form in his records. Although a note from 6-28-16 reported that at that time, the family felt PO's medical needs were too great for PO to transition to the community, they clearly later decided that having PO remain at the NF where he nearly died (the one he last resided in prior to moving to his current NF) was a poor option. Unfortunately, rather than seeking a community option, PO moved to the current Nursing Facility. In my discussion with the family, it was clear that they did not have sufficient information and therefore, had not fully considered how things could be individualized and different from his past community experiences. I also discussed the issue of CLO in person with PO, his LIDDA staff, and his guardian. In regards to barriers to his living in a community setting, his service coordinator stated that she felt his barriers to a transition to a community living option were primarily medical, and mainly related to wound care concerns, which needs to occur multiple times daily. She stated that she was concerned that his wounds would not heal, and he has circulatory problems and skin integrity issues. However, there are individuals residing in community settings who have such needs. There is no evidence that anyone attempted to address this barrier or locate a community setting that could meet PO's medical needs. Another barrier described was that he is now close to friends and family, and that it is difficult to find appropriate services locally to meet his high level of need and respect his interests and preferences. Both PO and his sister-in-law would consider community placement for him if a placement were available that would be safe and meet his needs and wishes, and be local. He enjoys socializing and would benefit from residing with a peer group that shared his interests, as he formerly lived with other people who had very different profiles from his, and were not as able to function and communicate independently as he. His service coordinator also believed that he would be required to attend day programming, which may not be consistent with his needs. To the extent a community setting that would meet his needs is not available PO has no meaningful choice to make about whether to remain in the nursing facility.

VIII. Bibliography

Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nursing ethics*, *23*(2), 142-153.

Calkin, Sarah, *Nursing Times*, 4-28-2011
https://www.nursingtimes.net/roles/nurse-managers/patients-still-afraid-to-make-complaints/5029171.article

Cella, M., Dymond, S., Cooper, A., & Turnbull, O. (2007). Effects of decision-phase time constraints on emotion-based learning in the Iowa Gambling Task. *Brain and cognition*, *64*(2), 164-169.

Harris, J. & White, V., *A Dictionary of Social Work and Social Care*, 281, Oxford University Press, January 9, 2018.

Joannou & Wolf (2011) Choice Making and Individuals with Significant Disabilities. https://www.lynchburg.edu/wp-content/uploads/volume-9-2013/JoannnouK-WolfJ-Choice-Making-Significant-Disabilities.pdf

Kim, S., Larson, S. A., & Charlie Lakin, K. (2001). Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. *Journal of Intellectual and Developmental Disability*, *26*(1), 35-50.

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual and Developmental Disabilities*, *114*(3), 193-222.

The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities? Research reviewed and summarized by Charlie Lakin, Sheryl Larson, and Shannon Kim University of Minnesota, Institute on Community Integration (UCEDD).March 2011.

Owen, A. L., & Wilson, R. R. (2006). Unlocking the riddle of time in learning disability. *Journal of Intellectual Disabilities*, *10*(1), 9-17.

Sparks, S. L., Pierce, T., Higgins, K., Miller, S., & Tandy, R. (2016). Increasing Choice Making in Students with Intellectual Disability. Education and Training in Autism and Developmental Disabilities, 51(4), 331.

Attachment A

Lauren R. Charlot, LICSW, PhD

e-mail: CharlotLR@outlook.com
Cell: 508-479-0157

Education

Doctor of Philosophy, Developmental Educational Psychology Ph.D., Boston College, Chestnut Hill, MA — 1994

Minor concentration: Brain – behavior relationships in psychiatric illness

Passed comprehensive exams with distinction

Masters in Social Work, Simmons College, Boston MA — 1982

Bachelors of Science, Suffolk University, Boston — 1980

Graduated first in class, College of Liberal Arts & Sciences

Appointments

Adjunct Professor — 2015 – Present
Department of Psychiatry, Brody School of Medicine
Eastern Carolina University, Greenville, NC

2000 - Present
Assistant Professor
Department of Psychiatry, UMass Medical School, Worcester, MA

Other Positions and Employment

7/7/17 –present **Client Reviewer – Department of Justice**

Review randomly selected group of individuals with IDD who are at or at risk of long term nursing facility placements. Offer expert testimony as required. Prepare reports regarding opinions related to any risk of harm to individuals.

7/14 – present **Director Becket Multidisciplinary Consultation Team for Individuals with Intellectual Disabilities and Mental Health Disorders**

(ID/MH)(Formerly the UMass team) Coordinate comprehensive multidisciplinary evaluations of individuals with highly complex neurodevelopmental disorders and medical/neurological comorbidities. Evaluations have been conducted for patients referred from multiple states/agencies, including remote evaluations using advanced video equipment. Formerly of UMHC.

1/09 - present **Consultant** - Member of the Center for START Services National Consultation and Training Team at UNH. Provide training and consultation regarding mental health of individuals with ID.

10/1/14 – 7/31/17 **Clinical Director, NC START East (A Program of RHA)**

Clinical Director for the NC START East program serving adults with

Intellectual and Developmental Disabilities and co-occurring mental health disorders and challenging behaviors, providing clinical oversight, supervision, clinical consultation and training to START Coordinators, crisis intervention and prevention services, Resource Center staff, and linkage services in collaboration with the local system of care.

12/98 -6/30/14 **Director Intellectual Disabilities Services/Various Roles**

See details below. Department expert on clinical services for individuals with Intellectual and Developmental Disabilities.

1/12– 6/30/14 **Director UMass Intellectual Disabilities/Mental Health Medical Home Project**

Developed and direct a unique pilot program serving 18 adults with ID and ASD who have significant mental health and behavioral challenges in a specialized service including primary care, psychiatry, neurology, behavioral consultation and care coordination in conjunction with Massachusetts Department of Developmental Services. Patients receive care from the team with a Care Coordinator, weekly rounds and close collaboration with family and caregivers, aimed at improving both health and behavioral outcomes for individuals with highly complex clinical presentations.

1/11 – 6/30/14 **Director IDS - Adolescent/Adult ID/ASD Clinical Services**

UMass Medical Center, Department of Psychiatry

Program development, expert consultation and training regarding the assessment and treatment of individuals with ID (Intellectual Disabilities), Autism Spectrum Disorders (ASD) and psychiatric disorders.

- Designed model for a pilot Medical Home and expanded expert multidisciplinary consultation service for adolescents and adults with ID/ASD in Central Massachusetts, served by the Department of developmental Services. Program will serve 30+ individuals with options for medical home services or consultation with extensive follow-up for patients with ID/ASD and severe challenging behaviors or co-occurring mental psychiatric disorders.

1/09 - present **Consultant** - Member of the Center for START Services National Consultation and Training Team at UNH. Provide training and consultation regarding mental health of individuals with ID. Current Co-Chair of Research Committee.

12/11- 3/15/16 **Federal Court Monitor** – State of Pennsylvania lawsuit related to care of individuals with ID in state mental hospitals. Provide review and oversight, and training on request, as part of an expert team responsible for assessment of compliance with settlement agreement.

10/13 **Invited Expert on Best Practices in Mental health and Intellectual Disabilities** – California state-wide project on quality indicators. Collaborated with other invited national and local experts on care of individuals with ID and psychiatric disorders for state-wide planning.

1/07 – 4/2014	**Consultant/Expert**- Massachusetts DDS Level III Monitoring Committee - Review of Level III behavioral treatment at the Judge Rotenberg Center, Canton, MA.
12/09 – 12/13	**Consultant/Expert**- Disabilities Rights California, Expert in work related to concerns regarding youth with Developmental Disabilities in Juvenile Justice Halls.
2/09 – 2/14	**Consultant/Expert –** Children's Home of Cromwell (CHOC). Consultation and training to clinical and support staff working with children with developmental and intellectual disabilities and behavioral health problems, served by the state Department of Child and Family Services. Many of the children have Juvenile Justice involvement and histories of aggressive and disruptive behaviors.
12/02-7/12	**Federal Court Monitor – Washington State** Oversight for implementation of a federal court settlement pertaining to inpatient psychiatric treatment of individuals with ID and psychiatric disorders. In addition to oversight of the Settlement Agreement, provided extensive training and consultative support to guide the development of inpatient psychiatric services to individuals with ID in the state psychiatric hospital setting. Advised and reviewed design and development of a comprehensive, multidisciplinary and multimodal approach.
2/09 – 1/1/10	**Consultant/Expert** – King's County Hospital, NYC. Consultation and training to the King's County Hospital medical staff regarding the assessment and treatment of psychiatric inpatients with Intellectual and Developmental Disabilities in response to Department of Justice citations and previous settlement order. Conducted multiple trainings for inpatient personnel including MDs, psychologists and nursing staff.
1/98-1/1/2007	**Program Director, Neuropsychiatric Disabilities Unit** University of Massachusetts Medical Center, Worcester Massachusetts- A 10 bed locked inpatient psychiatric unit providing care to adults with acute psychiatric illness and intellectual disabilities. Played primary role in designing the inpatient care model for patients with ID/MH. Conducted multiple Quality Improvement projects and designed training for nursing staff, medical students and psychiatry residents.
1990 - 1998	**Dir. Behavioral Treatment Services, Riverside Community Care, Norwood, MA.** - Emergency service -children, adults with psychiatric illness and ID and/or ASDs.
1982-1990	**Clinical Social Worker - Coordinator for Mental Health Team/Unit** Wrentham Developmental Center, Wrentham MA

Coordinator for specialized inpatient mental health unit team providing facility based care to individuals with severe mental illness, ID and behavioral disorders. The unit was located within the developmental center medical facility/infirmary and actually accepted community referred admissions. Coordinated services with colleagues from the Bost9n Children's Hospital.

Certification and Licensure

MA -LICSW # 105833	1985-Present
NC – LCSW	10/14-Preset

Professional Memberships and Activities

National Association of Social Workers	2016 – Present
American Association for Intellectual Disabilities	2007-2014
International Association for the Scientific Study of Intellectual Disabilities	2009-Present
National Association for the Dually Diagnosed	1998-Present
Board of Directors	
Advisory Board	

Awards

The Earl Loschen, MD Clinical Practice Award – Awarded at the NADD *Annual Conference, Denver Co. November, 2012*

Editorial Responsibilities

Research in Developmental Disabilities, Invited Reviewer	2005
Journal of Intellectual Disabilities Research, Invited Reviewer	2006 -present
Journal of Mental Health Research in Intellectual Disabilities, Invited Reviewer	2010 -present
Psychiatric Service, Invited Reviewer	2010
Journal of Social Policy and Practice in Intellectual Disabilities, Invited Reviewer	2012-13

Teaching Activities

Invited Training Series Psychiatry Residents and Child Psychiatry Fellows (Annual Training Series) Eastern Carolina University, Brody School of Medicine	November 2016-present
Invited Training for Massachusetts State DMH Medical Directors	June 2015
Grand Rounds Family Medicine – Developed a training for MDs with guidelines for preventing and managing aggressive patients with ID/ASDs receiving usual medical care in outpatient setting.	May 1, 2012
Developed 2 Day Curriculum for BCBA and graduate level students in	June 14, 15, 2012

Master’s degree program at Brock University, Ontario, CA.

June 2011

Multiple Dates

Developed curriculum for clinical and line staff working with youth with ASDs for facility based residential care setting, Cromwell, CT with multidisciplinary team. Also designed annual update training.

2000-2014

Annual

Forensic psychology fellowship program - overview of aggressive behavior in ID occurs yearly.

2000-Present

Designed and provided annual trainings for medical students, psychiatry residents and psychology fellows focusing on assessment and treatment of children and adults with Autism Spectrum Disorder and Intellectual Disabilities, psychiatric disorders or severe challenging behaviors. Trainings occur annually and as requested.

2000-2014

Multiple lectures to hospital EMHS re autism and developmental disabilities, as requested.

2000-2014

Mentor and assist in supervision of psychiatry residents rotating on the UMass Multidisciplinary Evaluation Team. Formerly same for students/residents on Neuropsychiatric Disabilities Unit, in conjunction with Medical Director for these programs.

2000-2014

Adult psychiatry - 2 part series on ID/MH for psychiatry residents occurs yearly.

2000-2014

Interclerkship Seminar for third year medical students. Annual training provided regarding mental health assessment and treatment of individuals with ID and ASDs

2000-2014

Developed additional, multiple 1 and 2 day trainings for Masters and PhD level mental health clinicians in the assessment and treatment of mental health and behavioral challenges in youth and adults with ID and ASDs for multiple organizations serving these populations.

.

Grants

Completed

Massachusetts EOHS — 2013-2014
EOHHS Health Care Infrastructure and Capacity-Building Funding for Hospitals and Community Health Centers
Lauren Charlot, PI
Title: A Medical Home Service for Adults with ID/ASD and Mental Illness.
Description: Designed an innovative healthcare program serving 18 adults with ID and ASD and severe behavioral health problems, and developed assessment package including development of database to study outcomes, and provide model for expanding services in the context of the ACO and healthcare reforms.
Role: (0.10% effort)

Completed

UMass Medical School – Commonwealth of Massachusetts and the Commonwealth Medicine Internal Grants Initiative 2006-2008

Lauren Charlot, PI
Title: Adverse drug events in adults with intellectual disabilities and mental health disorders.
Description: Conducted retrospective reviews of 198 psychiatric inpatients with ID to identify medical problems and adverse drug events. Developed a detailed chart review tool for the detection of adverse drug events, and initiated work to develop a screening instrument, based on in depth chart reviews of a subset of above (n=73 charts).
Role: (0.25% effort)

UMass Medical School and the EK Shriver Center– NICHD-R01 HD42807,
P30 HD04147 William McIlvane, PI
Title: Behavioral Studies of mental retardation and depression 2005-2009
Description: Conducted comprehensive mental health screening and cognitive assessment battery with youth with Intellectual Disabilities to identify neuorcognitive assessment strategies to characterize cognitive features of depression in youth, for whom usual verbal assessment means are often inadequate. Conducted inter-rater reliability checks for modified K-SADs and the Mood and Anxiety Semi-Structured Interview tool.
Role: Co-Investigator Role: (.25% effort)

Publications

Peer-reviewed publications

Kalb, L. G., Beasley, J., Klein, A., Hinton, J., & Charlot, L. (2016). Psychiatric hospitalisation among individuals with intellectual disability referred to the START crisis intervention and prevention program. *Journal of Intellectual Disability Research*, *60*(12), 1153-1164.

Charlot, L. & Beasley, J.B. (2013) Intellectual Disabilities and Mental Health: United States Research. *Journal of Mental Health Research in Intellectual Disabilities.* 6, 74-105.

Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. Non-psychiatric health problems among psychiatric inpatients with Intellectual Disabilities. *Journal of Intellectual Disability Research*, 55, 199-209 (2011).

Charlot, L., Deutsch, C., Alberts, A., Hunt, A., Connors, D., & McIlvane, W. Mood and anxiety symptoms in psychiatric inpatients with Autism Spectrum Disorder and depression. *Journal of Mental Health Research in Intellectual Disabilities* 1, 238-253 (2008).

Charlot, L., Deutsch, C.K., Fletcher, K., & McIlvane, W.J. Validation of the Mood and Anxiety Semi-Structured (MASS) Interview for Patients with Intellectual Disabilities. *Journal of Intellectual*

Disability Research 51, 821-834 (2007).

Charlot, L. & Beasley J. Specialized inpatient mental health care for people with intellectual disabilities. (2005) *Mental Health Aspects of Developmental Disabilities.* 8: 3, 100-103.

Shedlack, K., Levesque, C., Charlot, L. Bolduc, M., Silka, V. , Mikkelsen, E., Cole, Cole J. Nothing new under the sun: A case of neuroleptic withdrawal syndrome in a man with intellectual disabilities. *Harvard Review in Psychiatry*, 11:344-352 (2003).

Charlot, L. Mission Impossible : Developing an accurate classification of psychiatric disorders for individuals with developmental disabilities**.** *Mental Health Aspects of Developmental Disabilities* 6: 1, 26-33 (2003).

Charlot, L.R. , Fox, S., & Friedlander, R. (2002). Obsessional slowness in Down syndrome**.** *Journal of Intellectual Disability Research* 46: 8, 1-8 (2002).

Charlot, L.R. Developmental effects on mental health disorders in persons with developmental disabilities. *Mental Health Aspects of Developmental Disabilities.* Vol. 1; 2, 29-38 (1998).

Charlot, L.R. Irritability, aggression, and depression in adults with mental retardation: A developmental perspective. *Psychiatric Annals*, 27: 190-197 (1997).

Charlot, L.R ., Doucette, AD, & Mezzacappa, E. Affective symptoms of institutionalized adults with mental retardation. *American Journal on Mental Retardation* 98 (3), 408-416 (1993).

Books & Chapters

Charlot, L., Benson, E., Tasse, M, Fox, S. & Hassiotis, Depressive Disorders. In Eds. R. Fletcher & J. Barnhill. *Diagnostic Manual -- Intellectual Disability-II (DM-ID 2): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* NADD Press. 2017.

Pary, R, Charlot L. Bipolar and Related Disorders. In Eds. R. Fletcher & J. Barnhill. *Diagnostic Manual -- Intellectual Disability-II (DM-ID 2): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* NADD Press. 2017.

Bethea, T., Frazier, J., A., Bumberg, Bertelli M., & Charlot, L. Autism Spectrum Disorders, In Eds. R. Fletcher & J. Barnhill. *Diagnostic Manual -- Intellectual Disability-II (DM-ID II): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* NADD Press. 2017.

Charlot, L. Inpatient psychiatric care of individuals with Intellectual and Developmental Disabilities. Rubin, I.L., Merrick, J., Greydanus, D.E. & Patel, D.R. (Eds.) In *Rubin and Crocker 3rd Edition: Health Care for people with intellectual and developmental disabilities across the lifespan*. Dordrecht: Springer, 2016.

Charlot, L. Multidisciplinary Assessment of individuals with Intellectual and Developmental Disabilities. Rubin, I.L., Merrick, J., Greydanus, D.E. & Patel, D.R. (Eds.) In *Rubin and Crocker 3rd Edition: Health Care for people with intellectual and developmental disabilities across the lifespan*. Dordrecht: Springer, 2016.

Hasiotis, A., Steuber, K., Bini, T. & Charlot, L. Depressive and anxiety disorders in intellectual disability. E. Tsakanikos & J. McCarthy (Eds.) In *Mental Health in Intellectual Disability*. Springer 2013.

Charlot L.R., Fox, S., Silka, V.R., Hurley, A., Lowry, M., Pary, R. Mood disorders in individuals with intellectual disabilities. In R. Fletcher, E. Loschen, C. Stavrakaki, M. First .(Eds**.)** *Diagnostic Manual -- Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. (pp. 271-316). Kingston NY: NADD Press: Kingston, NY 2007.

Susan R. Gabriel, SR, Loschen, E, Reeve, A, Sanderson, D and Charlot, L. Mental disorders due to a general medical condition not elsewhere classified. In R. Fletcher, E. Loschen, C. Stavrakaki, M. First (Eds**.)** *Diagnostic Manual -- Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability***.** (pp. 221-232). Kingston NY: NADD Press: Kingston, NY. 2006

Charlot, L.R. & Mikkelsen, E.J. Commonly employed psychopathology instruments for individuals with intellectual disabilities. In : James Hogg and Arturo Langa (eds.) *Assessing Adults with Intellectual Disabilities: A service providers' guide*. Oxford: Blackwell Publishing. Pp 164-178. 2005.

Charlot, L. R. Use of Behavioral Equivalents for Symptoms of Mood Disorders. in P. Sturmey (Ed.) *Mood Disorders and People with Mental Retardation*. Kinston, NY: NADD Press. 2005.

Mikkelsen, E., Charlot, L.R. & Langa, A. The assessment of mental illness in individuals with intellectual disabilities In : James Hogg and Arturo Langa (eds.) *Assessing Adults with Intellectual Disabilities: A service providers' guide*. Oxford:Blackwell Publishing. Pp 52-73 2005.

Charlot, L.R., Abend, S., Silka, V.R., Kuropatkin, B., Garcia, O., Bolduc, M, & Foley,M. A Short stay inpatient psychiatric unit for adults with developmental disabilities. In Eds. John Jacobsen, James Mulick & Steve Holburn. *Contemporary Dual Diagnosis: MH/MR. Service models. Volume I: Residential and Day Services*. NADD Press : Kingston, NY. pp. 35-55. 2002.

Presentations & Abstracts

Invited Presentations:

Charlot L. DMID 2 Mood Disorders: Depressive Disorders and Bipolar & Related Disorders. Invited lectures: Brock University Dual Diagnosis Series, St. Catherine, Canada. June 2017

Charlot L. Autism Spectrum Disorders and Mental Helath Challenges. Invited lectures: Brock University Dual Diagnosis Series, St. Catherine, Canada. June, 2017

Charlot, L. with Robin Friedlander, MD, FRCPC, Leslie Smith, MD, Jennifer McLaren, MD. Searching for the Magic Bullet: The Evidence Base for Psychopharmacologic Treatment. START National Training Institute, Rye NY. May 2017

Charlot, L. & Friedlander, R. So Many Roads: Irritability in Individuals with IDD.

START National Training Institute, Rye NY.

May, 2017

Fletcher, R., Barnhill, J. & Charlot, L Pre-conference Sympsium on the DMID 2. NADD Annual Conference, Niagra Falls, Ca.

Nov. 2016

Charlot, L. Invited Lecture: Diagnosing Psychiatric Disorders in Autism Spectrum Disorders:Growing Up Uniquely, Service Net Annual dual Diagnosis Conference, Amherst, MA.

July, 2016

Beasley, JB, Caoili, A, Klein, A, Jacobstein DM & Charlot, L. START-ing With More Outcomes: SIRS in Action, START National Training Institute, Rye NY.

May, 2015

Charlot, L. Psychiatric Disorders in People with IDD: A Developmental-Bio-Psycho-Social Approach. AHEC Annual Conference, Greenville, NC.

Oct. -2015

Charlot L. Adverse Drug Events in People with Intellectual and Developmental Disabilities. Key Note. New Jersey ARC Annual Conference.

November, 2013

Charlot, L. Psychiatric Disorders and Autism Spectrum Disorders. Key Note Address. Health and Wellness Conference, Vancouver, BC, Canada.

June, 2013

Charlot, L. Understanding Aggression in Persons with ID and ASD. Southern Ontario Network of Clinicians, Toronto, Ontario, Canada.

June 2012

Charlot, L. When in Doubt: Rule It Out. Key Note Address. New Jersey ARC

Charlot, L. *Medical Problems that may Present as Acute Psychiatric Disorders*. Key Note address : Bringing Worlds Together ID:MH. Indianapolis, IN.

June 16, 2009

Charlot, L. *Mood Disorders and Intellectual Disabilities: How the DM-ID Can Help Improve Diagnostic Assessment*. Key Note Address. Ohio State 8th Annual MR/MH Annual Conference, Columbus Ohio.

September 28-29, 2010

Charlot, L. *Psychiatric Disorders in Autism Spectrum Disorders*. Key Note Address: Ohio State 7th Annual MH/MR Conference, Mental Health Aspects – Treatment & Support. Columbus/Worthington, Ohio.

September 28-29, 2010

Charlot, L. *The Top Ten Things to Remember about Individuals with ID and MH Disorders*. Key Note Address: South Eastern Ontario Community University research alliance in ID, 5th Annual Conference, Kingston, Ontario, Canada,

November 12, 2008

Charlot, L. Mood disorders in people with DD/MH. Key Note Address. Annual Conference on MH/DD. Red Deer, Alberta, Canada.

March, 2006

Charlot, L, Mood disorders in people with intellectual disabilities. Key Note Address. Ohio State University MH/MR 2nd Annual Conference.

2004

Charlot, L. (2004) Top ten things to remember about mood disorders and

intellectual disabilities. Key Note Address 21st Annual Conference of the National Association of the Dually Diagnosed. Vancouver, B.C	April, 2002
Charlot, L (2002) Understanding aggression; Mood and Anxiety disorders in individuals with DD. Washington Behavioral Healthcare Conference. Keynote address. Wenatchee, Washington.	May, 2002
Charlot, L (1998) Developmental effects on psychiatric disorders. Keynote address. Mental Health and Developmental Disabilities Conference. Bedford, NH.	September,1998

Local/Regional Conferences

Charlot, L. Assessment & Treatment of Behavioral Health Problems in Children and Adolescents with Autism Spectrum Disorder (ASD): A Developmental -Behavioral Perspective. *Cutting Edge Issues in Adolescent Psychiatry: Substance Abuse, Psychopharmacology, and Forensics*, Annual Conference of the American Society for Adolescent Psychiatry, Boston MA.	March 27-30, 2008
Charlot, L. *Assessment and Behavioral Treatment of Psychiatric Disorders in Autism Spectrum Disorders* (2008) International Dual Diagnosis Certificate Program, Brock University.	June 9-13, 2008
Charlot, L. *Assessment of Aggression in Adults with Intellectual Disabilities*, June 4 UMass Medical School and Massachusetts Department of Mental Health Annual Conference "Developmental Concepts and Issues in Law, Policy and Forensic Practice" Leominster, MA. Westboro, Ma.	June 3, 2008
Charlot, L. *Déjà vu all over again: Are antipsychotic drugs over prescribed for people with ID/MH?* Presentation to the International Congress of the NADD, Boston MA. .	March, 2006
Charlot, L. Mission impossible: Developing an accurate classification of psychiatric disorders in people with intellectual disabilities. International Congress V. Boston MA	March 2006
Charlot, LR & Silka, V. Neuroleptic withdrawal syndrome in people with ID. Grand Rounds at Mclean Hospital, Belmont MA.	2003
Charlot, L. Understanding and treating aggression in people with DD. McLean Hospital Grand Rounds, Belmont , MA.	Sept. 28-29, 2010
Charlot, L. & Bonney-Kuropatkin, B. Depression in adults with developmental disabilities. Psychiatry Grand Rounds. Children's Hospital, Boston Ma.	2002
Charlot, L. Developmental effects on psychiatric disorders. Mental Health and Developmental Disabilities Conference. Crotched Mountain Rehab Center, Greenfield, NH.	2000

Charlot, L. Depression in persons with mental retardation. Keynote address: Dual Diagnosis Conference. Manchester, NH.	1998
Lowry, M & Charlot, L. Aggression and self injury in persons with mental retardation and depression. Massachusetts Department of Mental Retardation Dual Diagnosis Conference. Holy Cross, Worcester, MA.	1997
Lowry, M. & Charlot, L. Aggression and self injury in persons with mental retardation and depression. The Second Annual Conference of the National Association of the Dually Diagnosed.. Boston, MA	1994

Committee Assignments and Administrative Service

Co-Chair UMass Department of Psychiatry Autism Academic Interest Group	2008-2014
Board of Directors - The National Association for the Dually Diagnosed	2001-2004

Community Service

IDD Medications Work Group: North Carolina	205-Present
Development of Practice Guidelines for use of psychoactive medications With patients with IDD	2012 – 2014
DDS Commissioner's Medication Review Committee – Participate in review of complex cases with a multidisciplinary team of experts in ID.	2005-Present
Advisory Board –The National Association for the Dually Diagnosed	2006
Invited ***Co-Chair for the NADD 23rd*** *Annual Conference of the National Association of the Dually Diagnosed.* San Diego, CA.	2004-2008
TENN-START, Chattanooga Tennessee Organization, Advisory Board Member	

.

Attachment B

Steward v. Smith
5:10-CV-1025-OLG
In the United States District Court for the Western District of Texas
San Antonio Division

CLIENT REVIEW REPORT OF LAUREN CHARLOT
Attachment B

	Document	Bates No.
1.	Texas Health and Human Services Commission, Form 1039, Community Living Options and Instructions, *available at* https://hhs.texas.gov/laws-regulations/forms/1000-1999/form-1039-community-living-options	US00253559-253568
2.	Texas Health and Human Services Commission, Form 1041, Local Authorities (LA) Individual Service Plan/Transition Plan – NF and Instructions, *available at* https://hhs.texas.gov/laws-regulations/forms/1000-1999/form-1041-individual-service-plantransition-plan-nf	US00253775-253800
3.	42 C.F.R. § 483.440, Condition of participation: Active treatment services.	US00253366-253372
4.	TEX. HEALTH AND HUMAN SERVS. COMM'N, *PASRR Webinar: Specialized Services for Nursing Facility Residents with IDD*, April 25, 2017	US00253271-253365
5.	40 T.A.C., Part 1, Ch. 17, Subch. A-E, Preadmission Screening and Resident Review (PASRR)	US00253388-253401
6.	40 T.A.C., Part 1, Ch. 19. Subch. BB: NF responsibilities related to PASRR	US00253402-253410
7.	TEX. HEALTH AND HUMAN SERVS. COMM'N, (formerly, Texas Department of Aging and Disability Services), *Explanation of IDD Services and Supports*	US00255966-255978
8.	TEX. HEALTH AND HUMAN SERVS. COMM'N (formerly, Texas Department of Aging and Disability Services), *Making Informed Choices: Community Living Options Information Process for Nursing Facility Residents*, February 2016	US-00253424-253429
9.	2016 PASRR QSR Compliance Status Interim Report	DefE-00096540
10.	Information Letter No. 15-33, Prior Authorization for Preadmission Screening and	US00253430-253432

	Resident Review Specialized Services, Prior Authorization for Customized Power Wheelchairs and Rehabilitative Therapy Requests from Elisa Garza, Donna Jesse, and Mary Henderson to Nursing Facility Providers and LIDDAs (May 13, 2015), *available at* https://www.dads.state.tx.us/providers/communications/2015/letters/IL2015-33.pdf	
11.	Information Letter No. 15-61, Preadmission Screening and Resident Review Habilitative Specialized Services from Michelle Martin and Elissa Garza to Nursing Facility Administrators (September 23, 2015) *Removed August 25, 2017*.	US00253433-253434
12.	Information Letter No. 15-84 Pre-Admission Screening and Resident Review – Reviewing and Requesting Changes to PL1s from Elissa Garza, Asst. Comm'r, Access and Intake to Nursing Facilities (December 31, 2015) *available at* https://www.dads.state.tx.us/providers/communications/2015/letters/IL2015-84.pdf	US00253435-253437
13.	Provider Letter No. 16-33 — Top Non-Compliance Trends with the Preadmission Screening and Resident Review (PASRR) Requirements from Mary Henderson, Asst. Comm'r, Regulatory Services to Nursing Facilities (August 31, 2016) *available at* https://www.dads.state.tx.us/providers/communications/2016/letters/PL2016-33.pdf	US00253503-253505
14.	Provider Letter No. 17-15 – Failure to Deliver PASRR Services from Mary Henderson, Asst. Comm'r, Regulatory Services to Nursing Facilities, (August 17, 2017), *available at* https://www.dads.state.tx.us/providers/communications/2017/letters/PL2017-15.pdf	US00253506
15.	Provider Letter No. 17-16 – Guidelines Regarding Plans of Correction Associated with a PASRR Violation from Mary Henderson, Asst. Comm'r, Regulatory Services (May 2, 2017), *available at* https://www.dads.state.tx.us/providers/communications/2017/letters/PL2017-16.pdf	US00253507

16.	Provider Letter No. 17-17 – Civil Money Penalty (CMP) Projects are Subject to Unannounced Visits to Ensure Project Implementation from Mary Henderson, Asst. Comm’r, Regulatory Services (June 21, 2017), *available at* https://www.dads.state.tx.us/providers/communications/2017/letters/PL2017-17.pdf	US00253508-253509
17.	PASRR TECHNICAL ASSISTANCE CENTER, Service Provider Promising Practices (Feb. 2013), *available at* https://www.pasrrassist.org/sites/default/files/attachments/PASRR_Service%2520Provider%2520Promising%2520Practices.pdf	US00253482
18.	42 C.F.R. 483, Requirements for States and Long Term Care Facilities	US00253483-253502
19.	TEX. HEALTH AND HUMAN SVCS. COMM’N, Local Authority for Intellectual and Developmental Disabilities Performance Contract, Attachment G (Amended Sept. 1, 2016)	US00253373-253387
20.	Tex. Health and Human Svcs. Comm’n, PASRR Level 1 Screening Form (May 2013, v. 1)	US00253470-253481
21.	Tex. Health and Human Svcs. Comm’n, PASRR Evaluation (June 2014, v. 3)	US00253438-243469
22.	PASRR Review Process and Service Coordination Participant Guide, July 2016	DefE-00055401-55459
23.	Nursing Facility records request letter	US00253268-253270
24.	LIDDA records request letter	US00253265-253267
25.	Spreadsheet: NF Transition Snapshot	DefE-01958693
26.	Nursing facility records for CB	US00095326-96480 US00175289-175394 US00182450-182480
27.	LIDDA records for CB	US00156123-156190 US00178160-178190 US00184897-185001
28.	Nursing facility records for DD	US00084204-84491 US00170615-170875
29.	LIDDA records for DD	US00112017-112110 US00164066-164104

		US00176769-176782
30.	Nursing facility records for KD	US00087802-88812 US00126000-127010
31.	LIDDA records for KD	US00156772-157005 US00159349-159360 US00159532-159559 US00159786-159794 US00159914-159926 US00160031-160043 US00161142-161204 US00177168-177179
32.	Nursing facility records for CE	US00156249-156571 US00171768-172079
33.	LIDDA records for CE	US00161804-161874 US00178531-178544
34.	LIDDA records for JuG	US00127364-127838 US00150619-151093 US00170945-170972
35.	Nursing facility records for JuG	US00175528-176159
36.	Nursing facility records for JG	US00084624-85791 US00177359-177997 US00182501-182503
37.	LIDDA records for JG	US00156191-156248 US00168827-168834
38.	Nursing facility records for SH	US00090800-91243 US00181467-181814
39.	LIDDA records for SH	US00108543-109153 US00178464-178530 US00182365-182391 US00185010-182357
40.	Nursing facility records for MH	US00155377-156122
41.	LIDDA records for MH	US00157006-157019
42.	LIDDA records for JM	US00136650-136883 US00180468-180725
43.	Nursing facility records for JM	US00153738-154538 US00180726-180868
44.	LIDDA records for MM	US00157714-158026 US00176802-177167
45.	Nursing facility records for MM	US00168950-169682 US00176572-176768 US00182576-182654

46.	LIDDA records for TM	US00112714-113281 US00128977-129544
47.	Nursing facility records for TM	US00112210-112293 US00164255-164525 US00178563-178614
48.	LIDDA records for PO	US00115836-115982 US00153415-163474
49.	Nursing facility records for PO	US00121372-121530 US00131851-132310 US00173251-173328
50.	Nursing facility records for JP	US00091366-91830 US00173792-174041 US00182504-182551
51.	LIDDA records for JP	US00156572-156771 US00160484-160537 US00161302-161331 US00177180-177267
52.	LIDDA records for RS	US00110953-110998 US00168835-168838
53.	Nursing facility records for RS	US00165777-166170 US00193017-193081
54.	Nursing facility records for BT	US00096481-96587 US00182421-182449 US00183538-185409
55.	LIDDA records for BT	US00114167-114428 US00134957-135218 US00172446-172453
56.	Review of Individuals in Nursing Facilities Questions & Considerations	US00258739-258741
57.	Joanne Watson, Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability, *Laws,* December 17, 2015	US00256046-256054
58.	Cognitive Dissonance Theory – Leon Festinger	US00255962-255965
59.	Charlie Lakin, Sheryl Larson and Shannon Kim, *The Effects of Community vs. Institutional Living on the Daily Living Skills of Person with Developmental Disabilities?* University of Minnesota, Institute on Community Integration (UCEDD). March 2011	US00255979-255982
60.	Shannon Kim, Sheryl Larson and Charlie Lakin, Behavioral outcomes of deinstitutionalization for people with	US00257145-257162

	intellectual disability: a review of US studies conducted between 1980 and 1999, *Journal of Intellectual and Developmental Disability*, 26(1) 35-50, 2001	
61.	Jacob Wolf and Kristin Joannou, *Choice Making and Individuals with Significant Disabilities*, University of Kansas	US00256020-256045
62.	Ann L. Owen and Rebecca R. Wilson, Unlocking the riddle of time in learning disability, *Journal of Intellectual Disabilities*, Vol. 10(1) 9-17, 2006	US00261289-261297
63.	Shannon Sparks, T. Pierce, K. Higgins, S. Miller and R. Tandy, Increasing Choice Making in Students with Intellectual Disability, *Education and Training in Autism and Developmental Disabilities*, 51(4) 331-343, 2016	US00261299-261311
64.	Georg Bollig, Eva Gjengedal and Jan Henrick Rosland, Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes, *Nursing Ethics*, Vol. 23(2) 142-153, 2016	US00261271-261282
65.	Matteo Cella, Simon Dymond, Andrew Cooper and Oliver Turnbull, Effects of decision-phase time constraints on emotion-based learning in the Iowa Gambling Task, *Brain and Cognition*, Vol 64, 164-169, 2007	US00261283-261288
66.	Agnes Kozma, Jim Mansell, and Julie Beadle-Brown, Outcomes in Different Residential Settings for People With Intellectual Disability: A Systematic Review, *American Association on Intellectual and Developmental Disabilities*, Vol. 144, No. 3: 193-222, May 2009	US00256612-256641
67.	Sarah Calkin, Patients still afraid to make complaints, *Nursing Times*, April 28, 2011	US00261298
68.	John Harris & Vicky White, *A Dictionary of Social Work and Social Care* 281, Oxford University Press, January 9, 2018	Available at: https://books.google.com/books?id=6GXrAwAAQBAJ&pg=PA281&lpg=PA281&dq=harris++and+white+learned+helplessness&source=bl&ots=XAeReu4v7K&sig=LNQkqfwUHIAGmD1dMMn8if5okzE&hl=en&sa=X&ved=0ahUKEwiz1fTz_ZHaAhWidt8KHYDGBL0Q6AEIPTAH#v=onepage&q=harris%20%

		20and%20white%20learned%20helplessness&f=false