PLAINTIFFS'
EXHIBIT

PPI 1280

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.	§	

PLANTIFFS AND THE UNITED STATES' EXPERT DISCLOSURE AND DECLARATION FOR BARBARA T. PILARCIK

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

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

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

4. Within the last four (4) years, I have not testified as an expert, either in a deposition or at trial, except in this case during the preliminary injunction hearing.

5. I have been retained by the Plaintiffs and the United States as a joint expert in the Steward v. Smith litigation. My compensation in this litigation is $150.00 per hour or $1,200 per day for my review, preparation of reports and statements, and for deposition or testimony, plus expenses. My compensation is not dependent on the outcome of this litigation.

Signed and dated: March 28, 2018

Barbara T. Pilarcik

Barbara T. Pilarcik

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 of Barbara T. Pilarcik was delivered via electronic mail and Federal Express to the attorneys for defendants at the addresses below:

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UNITED STATES DISTRICT COURT
WESTERN DISTRICT OF TEXAS
SAN ANTONIO DIVISION

Eric Steward, by his next friend and Mother, Lillian Minor, et al., Civil No. 5:10-cv-1025-OLG

Plaintiffs,

v.
Charles Smith, Executive Commissioner,
Texas Health and Human Services
Commission, et al.,

Defendants.

The United States of America,

Plaintiff-Intervenor,
v.

The State of Texas,

Defendant.

EXPERT REPORT OF BARBARA PILARCIK

1. PURPOSE

I was asked by the plaintiffs to conduct a review of a sample of individuals with intellectual and/or developmental disabilities (I/DD) who are residing in nursing facilities in Texas. The purpose of this review was to obtain information that would allow me to determine whether or not these individuals are receiving a comprehensive functional assessment of their habilitative needs, strengths, and preferences; whether they are receiving all of the specialized services they require to address those needs; whether they are receiving a program of active treatment; whether they are receiving professionally-appropriate individual service planning and transition planning; whether they would benefit from living in the community; and whether each person had made an informed decision to remain in the nursing facility.

2. QUALIFICATIONS

I have over 36 years of experience in the field of I/DD and another 17 years as a registered nurse. I have been a licensed registered nurse since 1963. My years of experience have included working in general, psychiatric, and obstetrics hospitals; in school and camp nursing; and for the Commonwealth of Massachusetts, Department of Mental Health. Most recently, I was employed for 32 years by The Association for Community Living (Association), a private, non-profit agency serving people with developmental disabilities throughout western Massachusetts. I served as the Executive Director of The Association for 8 years; I retired in 2016.

The Association was founded in 1952 by five mothers who were determined that their children would not need to leave their families and community in order to receive care specific to their needs, and that other children would also benefit from their efforts. From the beginnings of clinical nursery schools in the basement of churches, the Association today provides services throughout the four counties of Western Massachusetts, a population base of just under one million people. The Association has over 20 group homes that each serve between two and five individuals, with the exception of two eight-person homes that were previously Intermediate Care Facilities for persons with I/DD (ICF/IDD). The 20 residential programs provide staffing and services 24 hours a day, seven days a week. The services are habilitative and based upon each person's individual needs to achieve as much independence and self-determination as possible. In addition to the over 100 people served in the group home model, the Association also serves over 200 people in a Shared Living, or Host Home model. Individuals live with host families of their choosing, or with their biological family and also receive services based upon their needs and preferences. The Association has a large and active family services system, serving over 1000 families, and provides social and recreational activities, including a creative arts program, transition services, pre-school programs, and family support groups. The Association is also the regional Autism Center, serving over 1500 individuals and their families.

The Association opened the first ICF/IDD in Massachusetts over 30 years ago. This federally funded program provides active treatment to individuals with I/DD who also have complex medical needs. Today the Association serves individuals with complex medical needs in specialized homes. The Association has 31 people in five homes, all of whom have medical complexities, including tracheostomies, feeding tubes, implantable devices, customized wheel chairs, continuous oxygen, diabetes, serious seizures disorders, and rare conditions such as mitochondrial disorders. One of the homes has been designated to serve individuals who require mechanical ventilation to breathe. During the time the Association was licensed by the Department of Public Health under the ICF/IDD regulations, the Association met all licensing and regulatory requirements for active treatment. The Association, now known as Pathlight, is currently licensed by the Department of Developmental Disabilities.

I have many years of practical experience in planning, developing, evaluating, and delivering a range of services to individuals with I/DD, including those with complex medical needs. In addition to being the Executive Director of the Association, I have also been an expert consultant to help monitor settlement agreements in Virginia and the District of Columbia. I was an expert witness and testified in federal court in the *Rolland* case in Massachusetts, a lawsuit that affirmed the rights of individuals with I/DD in nursing homes to receive active treatment. I was a reviewer for the Quality Service Reviews in Texas from January 2015 until October 2015. I have evaluated services for individuals with I/DD for over 15 years.

I have presented at local, state, national, and international conferences on various topics including transition planning, supporting people during hospitalization, quality systems, safe practices, and shared living services. I have worked with organizations throughout the United States and as far away as China and Azerbaijan. I worked collaboratively with other leaders in the field to respond to an article in the *Journal of the American Academy of Pediatrics* to emphasize the importance of family-based services for children with I/DD and serious medical conditions. I wrote a grant which was funded by the

Massachusetts Developmental Disabilities Council to publish a manual titled *Supporting Individuals with Mental Retardation during Hospitalization.* The manual has been distributed throughout the United States and Canada and is part of the Quality Mall, an online resource of best practices. I served on the Massachusetts Department of Developmental Services strategic planning committee on health care. This committee implemented new policies and processes to support the health care needs of individuals served by the Department. The materials we developed have been used by other states. I have been the President of several local and state organizations in the human services field, and am currently a member of the Public Policy Committee of the Arc of Massachusetts and a Board of Director of the Corporation for Independent Living (CIL). CIL is a non-profit housing agency that has developed hundreds of homes for individuals with disabilities in Connecticut and Massachusetts. I also served for ten years on the Ethics Committee of the Baystate Medical Center Visiting Nurse Association.

My experience in providing services to individuals with I/DD over the past 36 years has proven that habilitative services help individuals attain skills and prevent or slow regression of skills. I have developed programs specifically for people transitioning from nursing facilities. These individuals have many complex medical needs and have been in an institution for most of their lives, often entering when they were children. There were no other options and the families often stayed involved with them. For example, we served one man who had a tracheostomy, a g-tube, and a pacemaker, was very tight with muscle spasms, and had repeated respiratory infections. He had lived with his family until the care needs became too great and then was placed into a facility. At one point, during a hospitalization for pneumonia, he was given last rites. With a comprehensive plan of care that included nursing support, physical therapy, a nutritionist, a massage therapist, and highly trained and skilled direct support staff, we were able to keep him out of the hospital for the next 25 years. It was the daily, consistent, and skilled care of our staff and their ability to recognize and quickly respond to any change in status that allowed him to live an active life, including a dream trip to Disneyworld --- tracheostomy, oxygen, feeding tube pump and all.

My experience encompasses direct service, nursing care, advocacy, policy development, program design, evaluation, management, and systems change in the field of developmental disabilities. For my curriculum vitae, please see Attachment A.

3. METHODOLOGY

As the lead expert reviewer and coordinator, I oversaw the client review process to promote consistency and reliability among the four expert reviewers. I developed a list of six areas of inquiry or probes, as well as various factors to consider in answering those probes, which were used as a guide for collecting and analyzing information, as well as reporting findings from the client review. I determined the relevant records to be requested and reviewed prior to the visits. I shared the probes and factors with the three other reviewers, Dr. Vickey Coleman, Lauren Charlot, and Natalie Russo, to ensure all reviewers understood and agreed with the approach to the review. I conducted two training sessions for the reviewers on the methodology for conducting the review, the sequence and materials to be read before the onsite visits, the process to be utilized during the visits, the sequence and persons to be interviewed, and the inspection of the physical environment, in order to answer the six questions. I conducted a brief, inter-rater reliability test, and then directed the reviewers to use the same probes and factors in conducting their reviews and generating their findings, in order to ensure that we considered the same issues, collected similar information, and answered the same questions relevant to federal and state PASRR standards, including specialized services and active treatment; service and transition planning; the most integrated setting; and informed choice.

I reviewed 20 individuals who were randomly selected from a list of all individuals with I/DD in nursing facilities in Texas. As part of the review I met with each individual in the nursing facility, with the nursing facility staff who knew the individual best, the service coordinator assigned to that individual, and whenever possible, the guardian or Legally Authorized Representative (LAR). All individuals agreed to be interviewed and I visited all in person. I also toured the facility and saw their room and any other locations within the facility where they spent time such as the dining room or an activities room.

After reviewing the records, collecting information during the on-the-ground review process and any follow-up telephone calls to guardians or service coordinators, and reviewing professional standards used to evaluate the adequacy of service planning and delivery, I analyzed this information and drafted a report for each individual (see Individual Findings and Conclusions, below). In each report I made a determination as to whether or not the Texas PASRR and community services systems as currently constructed and implemented are meeting the needs of each person. I then aggregated the information from all 54 individuals reviewed and made broader findings concerning the six key areas of inquiry for this review: (1) whether the individual received a comprehensive functional assessment of all habilitative areas that accurately identified all of the individual's strengths, needs and preferences; (2) whether the individual is receiving all needed specialized services with the appropriate intensity, frequency, and duration to address all need areas; (3) whether the individual is receiving active treatment; (4) whether the individual 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; (5) whether the individual would benefit from living in an integrated setting with appropriate community services and supports; and (6) whether the individual or their guardian has made an informed and meaningful choice to remain in a segregated nursing facility.

4. MATERIALS REVIEWED

I reviewed two years of clinical and case management records for each of the 20 individuals that I visited, which were provided to me on a secure online database. I also reviewed the most recent records on site at each nursing facility.

In addition to the nursing facility and Local Authority records that I read for each individual whom I reviewed, I also considered the Revised Active Treatment Standard, *Rolland v. Patrick*, Case 3:98-cv-30208-KPN, Document 456-2 Filed 08/02/2007; PASRR Requirements and Enhanced Community Coordination, DADS FYs 2016 and 2017 Contract, Attachment G; DADS Local Intellectual and Developmental Disability Authority PASRR Reporting Manual, Revised October 2015; DADS Instructions for Mental Retardation Authority Processing of OBRA PASRR Referrals, Part 483-Requirements for States and Long Term Care Facilities and the CMS Memo to State Survey Agency Directors of September 28, 2007 regarding PASRR and the Nursing Home Survey Process.

For a complete list of documents reviewed please see Attachment B.

5. PROFESSIONAL STANDARDS FOR INDIVIDUALS WITH I/DD

A professionally accepted program for individuals with I/DD begins with a thorough, accurate, and comprehensive functional assessment which takes into consideration the individual's age and the implications for active treatment at that stage in life; identification of the presenting problems and disabilities and where possible, their causes; identification of the individual's specific developmental strengths and developmental and behavioral needs; and identification of the individual's needs for services without regard to the actual availability of those services. The comprehensive functional assessment includes an evaluation of an individual's physical development and health, nutritional status, sensorimotor development, affective development, speech and language development, auditory functioning, cognitive development, social development, adaptive behaviors or independent living skills necessary for the individual to function in the community, and as applicable, vocational skills. Furthermore, the comprehensive functional assessment needs to be conducted by an interdisciplinary team of professionals.

The process requires that the relevant professionals involved in providing specialized services conduct their assessments within a specific range of time – approximately within thirty days of each other. This ensures that each professional is seeing the person's needs and preferences as they are, not as a varying set of skills that do not relate to each other. For example, a person who is experiencing difficulty in feeding, needs an occupational therapy assessment to determine what adaptive equipment such as weighted spoons or divided plates would help maintain self-feeding skills and a speech therapist to design a feeding protocol to ensure that staff are cuing the person to eat more slowly, takes sips of water between bites and sit in an upright position, thus minimizing the risks of aspiration.

The assessment, properly performed, will result in an identification of each habilitative need area and a description of a program of specialized services that will meet the identified needs of the individual and build upon their strengths. Goals for individuals with I/DD are based upon the concept of habilitation, unless they are recovering from an acute episode, in which case rehabilitation goals are indicated in the same way as for other people without I/DD in the same situation. Habilitation refers to a process aimed at helping individuals with I/DD attain, keep, or improve skills and functioning for daily living. It can include such services as physical, occupational, and speech therapy and various services such as behavioral supports, independent living skills, and social integration. Rehabilitation refers to regaining skills, abilities, or knowledge that has been lost or compromised as a result of acquiring a disability or due to a change in one's disability or circumstances. For example, an older woman with I/DD who falls and breaks her hip requires both: the rehabilitation services of physical therapy to strengthen her legs and regain balance; and on-going habilitative physical therapy to ensure that she can continue to work on her muscle strength and balance beyond the time for normal healing for an otherwise non-disabled woman. The habilitative therapy should also continue in all areas of her care and all the staff who care for her need to be trained in assisting her to follow her therapy program. The specific cognitive impairments of the person with I/DD means that repetition, consistency, and constancy are required to enable the individual to learn a new skill or maintain an existing one.

Habilitative services are particularly important for people with I/DD due to the fact that they often have concurrent health conditions such as weak muscle strength in persons with Down syndrome or cardiac problems in persons with Williams Syndrome. Many of the causes of I/DD have other systemic involvement that compromises general overall health. The cognitive impairment in persons with I/DD often means that they do not understand the importance of various healthy life style behaviors. While many of us in the general population understand the negative aspects of a diet of highly processed, high fat and high sugar food, it is often difficult for those with cognitive impairment to understand the long-term gain over the short-term denial. Ongoing support from trained professionals in I/DD can provide training that helps the person understand how to be healthy. In addition, many persons with I/DD do not use speech to communicate; often caregivers who are not trained in understanding non-verbal communication and behaviors mistakenly fail to understand that the individual with I/DD is using the only thing they have to communicate a need -- negative behavior.

Texas compartmentalizes specialized services into nursing facility and LIDDA specialized services, which appears to have the effect of focusing more attention on the former, and less on the latter. But the LIDDA specialized services, like Independent Living Skills, Day Habilitation, and Employment and Behavior Supports are precisely those that allow the individual to gain new skills, increase their independence, and engage in the community. These services also are vital to providing individuals the training and support they need to avoid future risks. Thus, they often are the pathway – if not the foundation – to professionally appropriate habilitation and active treatment for many individuals, as well as the transition back to the community.

Once the comprehensive functional assessment is complete, the intensity, frequency, and duration of needed specialized services are incorporated into an Individual Support Plan (ISP), prepared by an interdisciplinary team, that outlines the specific habilitative need areas that are being addressed and how those needs will be met. There must be a clear link between the specific objectives and the functional assessment data and recommendations. (42 CFR 483.440(c)(4)). The ISP is both a written plan and a process. While each therapist brings their specific expertise to the planning process, it is the dynamics of working collaboratively as a team that ensures that the individual is provided with a program of services that is comprehensive and builds upon each specialized service so that skill development can be reinforced throughout all therapies. This especially includes LIDDA specialized services, as they uniquely contribute to skill development and increased functional abilities. A program of Independent Living Skills (ILS) that focuses on purchasing toiletries can be reinforced by the occupational therapist at the therapy session through use of those items in learning how to properly do good oral hygiene.

The process also requires that all professionals meet on a regular basis to develop, coordinate, monitor, and modify as necessary the plan. Members of the team should change to reflect the changing needs of the individual. The process also requires the team to work together to assess the progress the individual is making on the various goals and determine if there is a need for a different intervention, or change in goals. The process ensures that the person is seen as a whole, and not fragmented into separate skill sets that are acted upon without regard for the strengths, needs, and preferences of the person. While this is true for every one of us, it is especially important for people with I/DD who do not readily understand abstract concepts, do not have a sense of future gain, and have difficulty understanding the relationship between daily therapy or skill-building sessions and long-term goals. The support of the team of individuals working in collaboration helps the person to remain motivated, to experience success in skill development, and to increase their abilities across all areas of their life.

An adequate ISP must include individualized goals, objectives, services to be provided (described in terms of the frequency, intensity, and duration of each service), and the professionals responsible for providing each service. It should be developed through a person-centered planning process. There must be a planned sequence for dealing with each of the objectives. Objectives must be stated separately, in terms of a single behavioral outcome; assigned a projected completion dates; expressed in behavioral terms that provide measurable indices of performance; organized to reflect a developmental progression appropriate to the individual; and assigned priorities. (42 CFR 483.440(c)(4)(i-v)). For example, a person who expresses a desire to learn to walk again will have a physical therapy assessment that identifies the specific skills that need to be attained, such as lower extremity strength and improvement of balance, and the methods that will be used to meet those needs, including measurable indicia of performance, projected attainment date, frequency of service, and the person(s) responsible for implementing the plan to regain walking skills. It will also include any adaptive devices or equipment that will assist the person in meeting that goal, such as a rolling walker.

Active treatment has been part of the standard for services for people with I/DD since the 1980s. The standard (42 CFR 483.440(a)-(f) and 42 CFR 483.120(a)(2)) states that each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services, and related services that is directed toward the acquisition of the behaviors necessary for the client to function with as much self-determination and independence as possible; and the prevention or deceleration of regression or loss of current optimal functional status. Active treatment must be carried over to all elements of the individual's life and settings where they live and receive services. For example, an OT goal that helps the individual to learn to use a fork to eat their food must be implemented every time the person eats food requiring a fork. To do otherwise confuses the individual regarding the task they are learning and impedes the attainment of this socially acceptable behavior. "Active treatment programs mirror normal living experiences such as leisure activities and social conversation at the dinner table. It must be clear that active treatment programs are far more than implementation of discreet formal training sessions or programs that are conducted at prescribed time by defined personnel. Learning occurs in the process of the normal rhythm of life and life experiences." (CMS Manual System, Publication 100-07, Transmittal 135, Revisions to State Operations Manual Interpretive Guidelines (February 7, 2015), Tag W196)

Active treatment requires that the ISP address training objectives in all habilitative need areas and that qualified I/DD professionals are available to implement these training objectives. This is essential so that all staff working with the individual understand how to provide carry-over throughout the individual's day and to ensure that the therapies reinforce each other and not work in opposition or overwhelm the individual with competing interests. Training objectives must, where appropriate, include activities of daily living, based on the client's assessed needs and as prioritized by the service planning team. (42 CFR 483.440(c)(6)(iii)). This enables the individual to remain as independent as possible and to enhance self-determination. Where needed, goals should address activities of daily living, such as brushing hair or teeth, bathing upper or lower parts of the body, and donning and doffing clothing.

The specialized services designed to achieve these goals are integrated into a single, coherent plan that clearly sets forth the individualized learning objectives, skill development strategies, and functional activities delivered through a collaborative effort of the various staff in the individual's life. Implementation of the plan also includes a description of the staff training necessary to achieve competency in assisting the individual to attain their goals. The plan describes the type of data and the frequency of data collection necessary to assess progress toward the desired objectives. The plan also describes any inappropriate individual behavior(s), and the replacement of inappropriate behavior with behavior that is adaptive or appropriate. The plan is then shared with all relevant members of the team and the individual and/or their guardian or family member and reviewed at regular intervals. The plan is changed in response to changing needs of the individual or attainment of goal(s) before the next regular meeting.

In addition to identification of goals to support the individual in obtaining skill acquisition or prevention of regression or loss of skills, the ISP must outline the transition plan for community living. The ISP must describe the relevant interventions to support the individual toward independence. (483.440(c)(6)(i)) Community placement is the most integrated setting for virtually all persons with I/DD and provides the greatest opportunities to interact on a regular basis with people without disabilities. The Supreme Court, in *Olmstead* found that institutional placement "perpetuates the unwarranted assumption that persons so isolated are incapable or unworthy of participating in community life" and "severely diminishes the everyday life activities of individuals." (*Olmstead v. L.C.,* 527 U.S. 581, 583 (1999)). People with I/DD who are placed in nursing facilities should not be assumed to be incapable or unworthy of participating in community living. In 2015 most people with I/DD, 87%, were living in their own home, family home or a small residential setting that is integrated in the community. Only 5% were living in nursing facilities or ICF/IDD institutions. (National Core Indicators Report At-A-Glance; Adult Consumer Survey 2015-2016). Given the wide-spread professional consensus that virtually all individuals with I/DD can benefit from integrated living arrangements with supports, this percentage has, and is likely to continue to increase.

People who live in small settings are able to choose more elements of their daily routine, including such basic decisions as when to go to bed and whether or not to sleep in on Saturday morning. They are more active in the daily rhythms of community life, such as leaving home in the morning to go to a day program and using public transportation. They frequently have a private room and do not have to share their bedroom space with a person not of their choosing. They can participate -- or not -- in neighborhood picnics or parties. Staff who are working with them are specifically trained to work with individuals with I/DD; their ISP is implemented in all settings and contains goals and objectives that are designed to increase independence and self-determination.

Beyond the professional consensus, I have direct experience in providing community-based living services for individuals who have resided for many years in nursing facilities, many of whom had complex medical conditions. We have successfully placed those individuals in both small group homes and in host homes or shared living settings. They have thrived in their new home, attended day programs, visited with their families on a weekly or more basis, and participated in social and cultural events including performing as part of a dance troupe. They delight in such as mundane things as raising vegetables in wheelchair accessible garden beds, helping to prepare their meals and smelling the fragrance of good cooking, sitting outside on the front porch and talking with their neighbors, going to the grocery store, attending the church of their choosing, and exercising at the local gym. Their lives are not confined to one setting, one routine, one group of people, no contact with individuals without disabilities except paid staff, and activities repeated through a set weekly schedule in the same segregated setting. The life they live in the community is extraordinary in its ordinariness and not the isolated, segregated life of an institution.

Informed choice is an element of all services for individuals with I/DD. Informed choice requires, but is not limited to, the provision of information about concrete options, that is presented in a manner that the individual can understand and relate to. It must be tailored to the specific learning style, experiences, fears, and concerns of each individual and/or family member. It must present information and community options in a manner that acknowledges and accommodates common features of I/DD such as a desire to please, fear of the unknown, resistance to change, and preferences for familiar routines. It must provide direct experiences of those options, and not simply written documents or pictures of an unfamiliar, future reality. For individuals who have been institutionalized for many months or years, it must be designed to address the vestiges of institutionalization, like dependency on staff, loss of autonomy, and lack of regular opportunities to make choices. Finally, and perhaps most obviously, it must be a real choice that is currently available and that is tailored to the individual's needs and preferences, not an abstract promise of something far away in place or time.

In sum, a professionally-appropriate and compliant PASRR program and *Olmstead* plan should prevent unnecessary admissions to nursing facilities and provide all needed specialized services and a program of active treatment to those who are admitted. This can only be accomplished through a comprehensive functional assessment that is used as a foundation to develop a single, integrated, person-centered plan of services which describes the goals, objectives, services, and transition supports necessary to allow individuals with I/DD to function with as much self-determination and independence as possible, and to make an informed and meaningful choice regarding living in the most integrated setting appropriate to their needs.

6. UNIQUE CHARACTERISTICS OF INDIVIDUALS WITH I/DD WITH RESPECT TO DECISION-MAKING

Individuals with I/DD present a unique set of challenges in ensuring that their choice is informed, particularly with respect to the choice of where to live or whether to move from a current living arrangement. Informed choice for individuals with I/DD requires awareness of and responsiveness to the unique characteristics of their developmental disabilities.

The interdisciplinary team must understand the cognitive development of the individual and how each individual learns best. This is best achieved through the comprehensive functional assessment (483.440(c)(3)(v)), which evaluates how the individual receives and retains information, uses reason and problem solving, and identifies the manner and type of information offered to the individual concerning choice options. It is simply not sufficient to develop a set of materials that are given to all individuals and assume that each or even any individual has gained a real understanding of that information. For most individuals with I/DD, information is best absorbed through direct experience and not through written or recorded information that does not place the person directly into the proposed situation.

Cognitive limitations must be acknowledged and accommodated, so that individuals with I/DD, and particularly those with significant disabilities do, in fact, understand the potential benefits and risks in determining whether to remain in a nursing facility. Information must be presented in straightforward and simple terms, with a sensitivity to the specific preferences and interests of the individual. Choices must be offered that accommodate those preferences, such as where to live, who to live with, and how to remain in close proximity to friends, family, and other important persons in their circle.

Individuals with I/DD often do not understand abstract concepts, time, or ideas that are expressed primarily through the written word. Individuals with I/DD have difficulty with processing and understanding information. They learn much better through actual experience and concrete examples. Thus, when a service coordinator reaches a conclusion about an individual's desire to not receive specialized services is based primarily on the isolated fact that "they gave no indication for specialized services" it can hardly be claimed that the individual has made an informed choice.

People who have been institutionalized for long periods of time do not have a frame of reference for understanding community living, and often fear the unknown and loss of familiar routines. Their first response often is reluctance to leave their current environment, even if that environment is a segregated institution. Gradual exposure to community activities through trusted relationships and positive experiences is critical to overcoming the vestiges of institutionalization.

Individuals who have been in a nursing facility also develop "learned helplessness" and gradually lose their skills simply because it is easier to have someone else do it for you. Time constraints and short staffing aggravate this effect. As a result, people are often rushed through their personal care routine or pushed to dining room in a wheelchair, rather than assisted to walk to their meals or taught to wash and dress themselves.

Years of isolation, institutionalization, or reliance on a familiar routine also can be overcome with practical exposure to community activities. LIDDA specialized services are uniquely positioned to provide this exposure through trips to the community with an Independent Living Service staff person, functional skill building in a Day Habilitation program, or even a part time job. Providing this exposure to the community can afford the individual some concrete experiences of community living and address fears or simply reluctance to modify years of the same routine in the same institution.

Because individuals with I/DD must often rely upon others for their daily needs, including food and personal care, they often learn what is necessary to please others and give the response they think they are supposed to give, whether it is to a family member or a staff person. It is not uncommon for nursing facility residents to say they want to remain in the nursing facility because staff promote this environment as the best or safest alternative. In the case of DK, her ISP indicated that she wanted to remain in the nursing facility, and yet she spoke softly to me at the conclusion of my interview "I am supposed to like it here, I am supposed to like it."

Informed choice also requires the elements that are present for any of us making an important decision, particularly one that impacts every aspect of our daily life, and far into our future, including a meaningful choice of an available alternative and strategies to address barriers to obtaining that option. The team supporting the individual should identify the barriers to living in the community and develop an action plan to reduce or eliminate those barriers. Identification of barriers requires that professionals on the team work collaboratively to resolve the barrier. For a person who requires specialized equipment like a Hoyer lift, the physical therapist must evaluate for the proper lifting system, determine how to obtain the correct lifting system, outline the staff training required to ensure proper transfer techniques, and adaptation of a living environment to include proper equipment. Other members of the team work with the individual to help her feel comfortable about the competency of the staff to perform the lift and ensure that there are enough staff on duty to safely perform the lift. This same approach is equally applicable to identifying providers in desired locations or ones that have demonstrated success in serving individuals with complex medical or other needs.

Helping an individual with I/DD to make an informed choice requires a thorough understanding of that person, through a comprehensive functional assessment; the presentation of information that is tailored to that individual's learning style, needs and preferences; the identification of barriers and an action plan to resolve the barriers; direct experience which places the individual into the proposed situation; feedback from the individual so the team can assess the level of understanding; and a trusting relationship between the individual and members of the team, particularly the service coordinator. The service coordinator holds the unique role as the bridge between the current situation in the nursing facility and the proposed or future situation in the community. If the relationship with the service coordinator is a series of five to fifteen-minute visits once a month, it will be very difficult for the individual to believe that the proposed setting, which is full of unknowns, is better than the known setting at the nursing facility.

7. AGGREGATE FINDINGS

A. Summary of Findings from All Reviewers

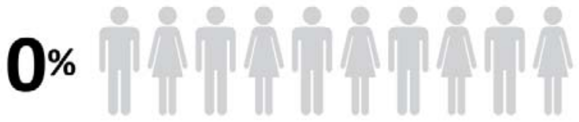
Each of the four experts who conducted this client review presented aggregate findings in their reports. Combining the data from each of these experts yields the following summary findings for the 54 individuals in the client review:

 = 10% of reviewed individuals

1. **Comprehensive Functional Assessment**
   None of the 54 individuals received a Comprehensive Functional Assessment (CFA). Without a CFA there is no basis for planning and delivering necessary specialized services. The result is a service plan that often fails to address basic habilitative needs and fails to identify needed services. It also results in a plan that has low expectations, lack of clear direction, fragmentation, and lost opportunities for maintenance or growth of skills in independent living and self-determination.

2. **Specialized Services**
   None of the 54 individuals was receiving all necessary specialized services. Every individual reviewed was denied opportunities to increase skills, avoid deterioration, and maximize independence and self-determination. Specialized services are a core component of active treatment.

3. **Active Treatment**
   None of the 54 individuals was receiving active treatment. Without active treatment, none of the 54 individuals was receiving a program that meets the federally-mandated standard of care and that is directed toward the acquisition of behaviors necessary for the individual to function with as much self-determination and independence as possible.



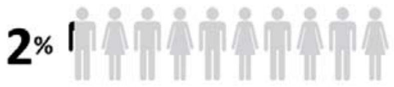
4. **Individual Service Plan (ISP)**
   Only 1 of the 54 individuals had a professionally appropriate ISP.[1] Without this, individuals do not have a plan that contains goals for transition, a plan for the individual to make an informed choice about the community, an individualized description of the community, or strategies to address barriers to community living.

5. **Community Living**
   53 of 54 individuals are appropriate for and would benefit from living in the community. As the Supreme Court stated in *Olmstead v. L.C.,* institutional placement "perpetuates the unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." It is a widespread professional principle that persons with I/DD thrive best living in and experiencing the normal rhythms of everyday community living.

6. **Informed Choice**
   46 of 54 individuals or their guardians have not made an informed choice to remain in a nursing facility. As a result, they remain unnecessarily institutionalized in these segregated settings.

Only 2 individuals had an ISP that included a specific description of transition options in Phase II of Section 9.

Only 1 individual or their guardian had visited community living or support providers.



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[1] 2 individuals had missing or mostly incomplete ISPs in their record.

Only 3 individuals had barriers to living in the community addressed.

Despite the lack of specialized services to address habilitative needs, active treatment to maximize independence and self-determination, individualized transition planning, concrete steps to address barriers, adequate information about community options, and actual community experience, at the time of the review:

72% of individuals (39) expressed an interest in learning more about the community.

52% of individuals (28) were interested in transitioning to the community.

B. Aggregate Findings from My Review

i. Comprehensive Functional Assessment (CFA)

None of the individuals reviewed had received a comprehensive functional assessment. The comprehensive functional assessment must take into consideration the person's age, identify the presenting problems and disabilities, and then identify their strengths, developmental and behavioral needs, and services necessary to meet those needs. While most of the individuals received both the PASRR Level I screening and the PASRR Evaluation and various nursing facility assessments, these assessments were not performed at the same point in time by an interdisciplinary team of professionals. They were often done weeks or months or even sometimes years apart, and were not part of a single, coherent assessment and program plan. Therapies, such as occupational therapy (OT) or physical therapy (PT) were usually done separately from the initial assessments and not integrated into a single plan of services. As a result, there was no comprehensive and current description of the individual's needs that would allow the interdisciplinary team to develop a cohesive service plan.

Areas of assessment that were often lacking were social development, cognitive development and adaptive behaviors, or independent living skills necessary for the client to be able to function in the community. The result of this lack of a comprehensive functional assessment has resulted in a plan of services, as captured in the Individual Service Plan (ISP) that tends to focus on minor skill development goals. For example, as in SBo's goal of "play keno and video games," without recognizing that she has a GED and has attended college. For SBa, there was no reliable assessment of her cognitive development, but instead an evaluation which determined her IQ to be 0, which it surely is not. The social assessment of SH does not recognize that he lived with minimal supports in the community for all his life and has a strong desire to return to his apartment. Belatedly, he is now receiving transition planning and hopes to obtain Section 8 housing and return home, mostly because of the efforts of a service coordinator working apart from the ISP.

The CFA should form the basis for planning and delivering the services and supports that increase and/or maintain skills, and prevent regression. For people with developmental disabilities, as is true for health care in general, all effective services begin with a thorough understanding of the needs and strengths of the person receiving care. To shortchange this process by conducting it in a fragmented manner results in a service plan that has low expectations, lack of clear direction, and lost opportunities for maintenance or growth of skills in independent living and self-determination. Instead, as with many of the individuals in this review who lacked a CFA, service planning and delivery resulted in a loss of optimal functional status.

ii. Specialized Services

None of the individuals reviewed were receiving all of the specialized services that they needed or that were recommended by their interdisciplinary teams. Few were receiving any LIDDA specialized services except service coordination. One individual (BH) has had three different service coordinators in two years and has not had a quarterly meeting since September 2015. Another individual (SE) has refused service coordination from her assigned male service coordinator because she believes he is from the "blood bank," and yet she accepts services, supports, and even coordination from female nursing facility staff. The LIDDA has not assigned a different service coordinator and continues to send the same rejected service coordinator to meet with her. For many individuals, there was a lack of communication between service coordinators and nursing facilities that resulted in needed services not being recommended, continued, or provided with the frequency, intensity, or duration needed.

There was a noticeable and persistent lack of understanding or reluctance to use the PASRR services provided by the nursing facilities. Several nursing facility staff stated that the PASRR system is difficult to use and they prefer to use restricted insurance systems to fund, on a time-limited basis, necessary therapies. This approach has resulted in therapies, in particular OT, PT, and ST, being provided later than necessary, on an intermittent and time-limited basis, and often in response to a precipitating event, rather than on an ongoing basis to achieve identified habilitative goals. As a result, several individuals have lost skills (AH, BH, BF, SH, SBa, DH, LB) or suffered from new wounds (SBo, JM, DH, LB). BH, who has not received PASRR habilitative PT, despite strength and balance issues, fell and broke her hip subsequent to my visit. In addition, since the nursing facility staff do not understand the PASRR system, they rarely consider other specialized services such as Independent Living Skills Training (ILS), Day Habilitation or Behavioral Health Services. As a result, some people have just begun to receive ILS services after years of confinement in a nursing facility, while many individuals are still not being considered for these services. Others who would benefit from Behavioral Support Services have not received them and have suffered harm as a result (SBa, SE, VC, LB, AH, DPar).

Specialized services are fundamental to ensuring that the individual receives a continuous, aggressive active treatment program. The provision of intermittent specialized services (SBa, JM, DPay, DH, LB, AH, DPar, VC, DK, SBo, BH, and SS), the long delay in receiving services (SH, DPay, AH), and the absence of recommended or necessary services (DH, SE, DPar, CN, JM, TS, SH, WD, SBa, CB, LB, SBo, VC, BF, AH, BH, DK, DPay, SS, and AS) has resulted in a lack of active treatment for these individuals.

iii. Active Treatment

None of the individuals reviewed received a program of active treatment. None received the foundational comprehensive functional assessment necessary to design a program of active treatment; none received all of the necessary specialized services and other supports necessary to implement a program of active treatment; and none received all needed specialized services with the frequency, intensity, and duration, delivered consistently and continuously throughout the week, to constitute a program of active treatment. As a result, none received a program that resulted in increased independence and improved functional skills or at least the prevention of regression and loss of skills.

Active treatment builds upon a comprehensive functional assessment, conducted by an interdisciplinary team of professionals to produce a single, integrated program of services. The assessments provide clear goals and assign responsibility for the provision of specialized services across the spectrum of the individual's life on a day-by-day basis. Active treatment requires that all those who work with the individual are trained in the person's plan and have the competencies necessary to fulfill the goals and objectives of the plan. The plan is implemented consistently and continuously throughout the day, every day, of the individual's life. While some services, such as Independent Living Skills, might take place a few times a week in the community, all staff who work with that individual need to be aware of the goals worked on in that program, so that they can be reinforced whenever the opportunity arises. For example, SS enjoys make-up; she would gain functional skills through an ILS program that takes her out into the community to purchase make-up and an occupational therapy (OT) program that maintains her self-care skills in applying make-up; the nursing assistants can carry-over the OT program in the morning when they assist her in her ADL care and discuss the items she purchased during her ILS outing.

OT skills also take place outside the therapy room and involve direct support staff who are assisting the person to dress or toilet in the evening. Speech therapy (ST) develops a protocol around safe feeding for the individual with dysphagia, and then trains staff in the procedure, but it is the consistent implementation of that protocol, at every single meal, that ensures that the individual will not develop an aspiration pneumonia.

Habilitation is central to active treatment. Specialized services are designed to be habilitative, in order to ensure that there is the acquisition of behaviors necessary for the client to function with as much self-determination and independence as possible and the prevention or deceleration of regression or loss of current optimal functioning. Residing in a nursing facility does not mean that the person has no life left to enjoy and cannot continue to grow and achieve new skills, maintain their level of functioning and be able to exercise some of the same rights as other citizens. The pursuit of happiness does not end at the entrance of the nursing facility.

I am aware of data from the Centers for Medicare and Medicaid Services indicating that Texas' nursing facilities have been rated the worst in the nation. (Kaiser Family Foundation, 2015). I am not surprised by that ranking given my own observations of Texas nursing facilities that I visited during my individual reviews.

iv. Individual Service Planning

All but one individual in the review lacked a professionally appropriate individual service plan (ISP) based upon person-centered planning principles. One individual (TS) is in what appears to be a minimally responsive state and declining; his ISP is appropriate for his current level of functioning. Another individual (SE) has refused to meet with her service coordinator and the LIDDA has not assigned a female service coordinator to work with her, leaving her with no relevant ISP and certainly no person-centered plan.

All of the other ISPs lack of a comprehensive functional assessment. The ISP for AS has very little information about his health, including no mention of a hospitalization and only a minimal description of the impact of his insulin dependent diabetes or cerebral palsy. ISP goals in this review were usually not goals at all, and almost never goals for developing new skills. Instead, they were uniformly based on simple tasks such as merely attending activities in the nursing facility, or, in reality, goals for staff such as "freedom to choose what I want" (VC). A frequent "goal" is "I want to continue residing in the nursing facility." (CB, AS, AH) or even documentation in the SPT meetings that the individual is not interested in community placement, even when the person is consistently stating that they want community placement (SE, SH, AH).

Very few of the ISPs reviewed had any goals directed to gaining daily living skills. Most ISPs have two or three goals with AH, SS, and DPay having only one goal and BH with no goals. These goals are not designed to increase functional abilities or prevent regression. DPay's one goal is to receive his chewing tobacco each morning from the nurse. AH, who has lost skills, had her goal of "maintain her best level of physical functioning" discontinued. There is no explanation for why this goal was dropped, and it is striking because her fervent desire is to return to living in the community, as she did all her life prior to her admission to the nursing facility. Several goals are expressions of basic rights for any nursing facility resident such as "attend activities of (their) choosing" (AH, LB, JM, SS). These poorly defined and meager goals are a result of the lack of an interdisciplinary team of professionals, working collaboratively together as part of the comprehensive functional assessment, and developing a meaningful, person-centered plan.

Often the quarterly meetings to review the ISP and the progress of the individual are conducted with only the service coordinator and one or two other nursing facility staff (AS, DPar, CB). Several individuals have family members who are active in their lives, and there is no contact between the service coordinator and these family members and little if any participation by them in the ISP process (DPar, AS, CB).

The ISP is not only a collection of information about the individual; it is a plan that describes the efforts of the professional team who come together to ensure that the individual is provided with the specialized services that will enable him or her to live with their highest level of functioning and self-determination. Executed according to the long-held professional standards in the field of developmental disabilities on person-centered planning, it ensures that each person, regardless of their abilities can still grow and enjoy each day.

v. Benefit from the Community

With the exception of TS, who is in a minimally responsive state, every individual I reviewed is appropriate for and would benefit from living in the community. They are no different or needier than other individuals who already live in the community. The other nineteen individuals share the same characteristics of people with I/DD who live successfully in the community in Texas, Massachusetts, Virginia, and other states. All of the 20 individuals had lived in the community for most of their life prior to the admission to the nursing facility. CN, DPar, DH, and AS had lived at home with family until a family event or health event caused them to be admitted to a nursing facility. SH, SBo, AH, SE, and SS had lived semi-independently in the community with minimal supports. LB, DK, VC, BF, JM, DPay, and TS had lived in community group homes or ICF/IDD programs, and BH, SBa and WD had been served by the mental health system. DH and LB both came to the nursing facility for a short term stay to regain lost skills, but sadly, both of them have lost skills. DH had broken his hip but was able to stand and do one person assist transfers. Today he is confined to a Geri-Chair and has no mobility whatsoever. LB, who was admitted to the hospital for GI bleeding was found to have hemorrhoids and inexplicably now is confined to a nursing facility. She, along with JM, DH and SBo all have suffered from decubiti since their admission to the nursing facility. BH, who had shown a decline in mobility skills, fell and broke her hip shortly after my visit. DPar, who has Down syndrome, has been confined to a nursing facility for over twelve years, since the death of her parents. She is very similar in her skills and abilities to other individuals with Down syndrome that I have served over the years, successfully in host homes, group homes, and supported apartments and in employment. She expresses an interest in reading and her semi-private room is filled with books, and yet she is not even able to visit a library or a book store, let alone participate in a book discussion group as individuals with Down syndrome do in the social programs our agency provides.

With the exception of TS, the constellation of medical needs presented by these individuals can all be provided in the community. Some examples of medical conditions served in the community for people with I/DD are dialysis, tube feedings, serious seizure disorders, implantable devices, wheelchair mobility and transferring assistance, neuromuscular disorders such as cerebral palsy, insulin dependent diabetes management, cardiac conditions, and respiratory diseases. VC is in a nursing facility because her group home would not provide the Hoyer lift she now requires to transfer. BF was told it was time to "retire", which is somehow synonymous with nursing facility placement. The agency actively pursued an order from the physician for placement in a nursing facility. In my interview, her sister stated that she plans to move back in-state and remove her from the nursing facility. AS's family plans to have him return to the community. His service coordinator was totally unaware of this stated desire and had never contacted them, despite the fact that someone from the family visits daily and accompanies him on all medical appointments.

vi. Informed and Meaningful Choice

Of the twenty individuals reviewed, SBo and SH have both affirmed that they want to return to the community and their ISP reflects that this is their desire. CN, WD, and TS all have guardians who have made an informed choice to remain in the nursing facility.

The remainder of individuals, fifteen in all, have not made an informed choice to remain in the nursing facility, despite the fact that it is the long-term plan for all fifteen. AS, DPar, and CB all have the same statement written by the service coordinator regarding interest in receiving specialized services including the LIDDA service of ILS: __ "gives no indication that s/he is interested in receiving specialized services". All three of these individuals have active family members, yet the service coordinator has never spoken to any of them regarding their hopes and plans for their family member. Both AH and her sister have repeatedly stated that she wants to return to the community and yet her ISP states that her long-term plan is to remain in the nursing facility. When questioned, the service coordinator stated that there were few if any programs in the area that were available for her.

Despite LIDDA requirements for service coordinators, only one individual, DPay, has been provided with the opportunity to actually visit a community program. Two individuals, CN and WD, had guardians who declined opportunities to visit community providers. Despite PASRR requirements, only DPay, SE, CN and SBo have been offered ILS, which would give them an opportunity to experience the community with a specially trained staff person. However, none of them were receiving ILS at the time of my visit; SBo due to her health concerns and the other three due to staffing issues. Only DPay has ever received the recommended ILS.

There was no evidence that any of the individuals, other than SH, received an individualized explanation of community living options that accommodated their cognitive disabilities and reflected their preferred communication styles. Similarly, there was no evidence than any of the individuals who have been institutionalized for years, like SS, were provided any special efforts to address the consequences of their institutionalization on their ability to make an informed choice. And there was no evidence that service coordinators or others addressed specific concerns or fears about transition to the community.

Very few individuals have had meaningful opportunities to participate in community activities; in fact most have few if any such opportunities. Only four of 20 individuals reviewed have regular opportunities to leave the nursing facility and spend time in the community; SH, JM, CB, and WD.

Section 9, Phase 2 of the ISP is blank for every individual I reviewed, other than SH. None had all barriers to transition identified, even though the individual, a family member, and even the service coordinator were aware of such barriers, such as a lack of accessible or competent providers. None of their ISPs adequately described actions to address such barriers, and not surprisingly, none contained any resolutions or strategies for alleviating them. For only three individuals, CN, SH, and SBo, were concrete actions taken to address barriers. The section is not individualized to the person, but, instead simply results in a checked box that the person prefers to remain in the nursing facility, even if that alleged “preference” is due to familiarity with or pressure from staff, or understandable fear of change for persons institutionalized for years. All of us, at some level, fear change and become customized to our routines; we prefer the known over the unknown. But informed choice requires that we be provided with information in a manner so that we can understand our options, experience alternatives, communicate preferences, and develop confidence that fears and concerns are addressed. The lack of individualization became evident in my conversations as 12 individuals or their guardians [SBo, LB, SH, AH, DH, DP, SS, AS, SBa, SE, BF, DK], indicated a desire to learn more about the community and 10 individuals or their guardians [SBa, SH, LB, DK, AH, DH, AS, SBo, SE, BF], expressed an interest in transitioning to the community. They told me that they *did* want to go out of the nursing facility for community outings and *are* interested in living in the community. DK poignantly stated that “I am supposed to like it here, I am supposed to like it.”

These individuals followed different paths to their nursing facility: loss of self-care skills, a temporary down turn in health, or an unforeseen catastrophic family event. Unfortunately, for fifteen of the twenty people there is no return to the place they left behind. It appears the assumption is made that once a person enters the nursing facility, the default option is to remain in that segregated setting for the rest of their life. The individual is seen as “incapable” of participating in community life; the low expectations of the system and the consequences of institutionalization becomes a self-fulfilling prophecy as individuals become more accustomed and dependent on the regimentation, lack of privacy, limits on their ability to access normal community activities, engage with family and friends of their choosing, and remain as independent as possible.

8. INDIVIDUAL FINDINGS

Individual: CB

Italy, Texas Review Date: August 24, 2017

CB is a sixty-four-year-old gentleman who resides in a nursing facility in Italy, Texas. He was admitted on June 26, 2012. There is no information in the records I reviewed that provides any clue regarding his previous residential placements. The PASRR documents list previous placement as unknown, list an address in Bellmead, Texas, and states that it was an ICF/IDD facility. Neither the service coordinator nor the nursing facility staff were knowledgeable regarding his prior placements or community homes, even though this information is vital for his service coordinator to have a full understanding of his community experiences. CB's sister visits every week and could likely provide this information, if asked.

When I entered the nursing facility, CB was by the front door in his wheelchair. He opened the door for me, something he likes to do for people entering the building. I met with him after meeting with the LIDDA and nursing facility staff. CB was seated at a four-person table and engaging in conversation with one other gentleman. CB readily agreed to speak with me. He told me that he likes to pick up the trash around the facility, play ball, and play music. CB sees his sister every weekend. He is described by nursing facility staff as outgoing, friendly and helpful. He likes to shred paper as a job that he does for nursing facility staff and is considered a "resident volunteer". CB participates in all the activities at the facility including bingo, music, and church. He likes to go on community outings and is an Elvis fan. He uses a wheelchair which he can propel and he can travel in a regular car.

CB did not receive a comprehensive functional assessment of all habilitative areas that accurately reflect his strengths and needs. He has not had assessments in the areas of sensorimotor development, affective development, auditory functioning, cognitive development, social development, adaptive behaviors, or vocational skills. He has had two PASRR Level 1 screenings, conducted in September 2015 and June 2017. He had a PASRR Evaluation (PE) on March 25, 2014 which was positive for intellectual and developmental disabilities (IDD) and for mental illness (MI). The MI assessment date is listed as September 18, 2013. The PE did not recommend any specialized services other than service coordination for his IDD and a psychiatric diagnostic interview for his MI. The PE states that CB needs assistance with most self-care needs and one-person assistance but did not recommend any therapy or any therapy assessments. It was not until three years later that CB finally received occupational therapy (OT) in March 2016 and physical therapy (PT) and speech therapy (ST) assessments in November 2016. CB eventually received a psychiatric evaluation on February 23, 2016. CB had various nursing assessments during his time at the facility in the areas of skin integrity, pain, safety issues, wandering, fall risk, and significant issues. These nursing assessments are standard to all individuals within the facility and do not provide information specific to individuals with IDD. The assessments are not comprehensive in that they are done over a widely varying time period and do not capture a picture of CB's strengths, preferences and needs at a singular point in time or in relevant habilitative areas.

CB is not receiving any specialized services, except service coordination. Although he would benefit from habilitative PT, OT, and ST as well as behavioral supports and a customized manual wheelchair (CMWC), CB is receiving no nursing facility specialized services. He is not receiving any behavioral supports, although he did receive a psychiatric diagnostic evaluation that indicated that he would benefit from behavioral treatment. He was evaluated for a CMWC in August 2017 by OT. The service coordinator stated that he also is being evaluated for OT, but that still has not occurred. He receives regular screenings from the therapy department but has never received any PASRR habilitative therapies.

At most, CB has received only intermittent nursing facility rehabilitative therapy. In November and December 2016, CB received rehabilitative PT, in March and April of 2016, he received rehabilitative OT, and in November 2016, CB received rehabilitative ST which ended in January 2017. All of the services were of limited intervention, usually one month or less. CB would benefit from ongoing habilitative OT and PT due to his immobility and need for assistance with his self-care needs. OT and PT can assist CB to develop his muscle strength, balance, coordination, wheelchair propulsion, transferring skills and ADL skills. It is important that he maintain his current level of independence and be given the opportunity to increase his skills. The therapy screenings and services with which CB has been provided at the NF are exclusively done for short term rehabilitation, not habilitation, with no attention to the retention of skills and prevention of regression.

CB would also benefit from such LIDDA specialized services as Independent Living Skills (ILS) and Day Habilitation services (DH). He stated that he would like to have support in the facility and to engage in community activities through ILS. CB also said that he would like DH, given his proficiency in tasks such as paper shredding and being a “resident volunteer”. The service coordinator thought ISL and DH might be “a good idea” but could not be provided because of difficulties with transportation. The nursing facility staff also thought DH services would be beneficial and stated that transportation would not be a problem, since he could utilize the community transportation system to get to a DH program. CB does not need a wheelchair van for transportation, as he uses a regular car when his sister picks him up nearly every Sunday. Although he has received psychological services through the nursing facility, he does not display challenging behaviors.

CB is not receiving a continuous program of active treatment that is consistently implemented. CB did not have a comprehensive functional assessment which would have provided the information about his needs, strengths, and preferences in order to ensure that he would receive the necessary specialized services. As a result, he has not received the habilitative services of PT, OT, and ST which would enable him to continue to acquire the skills necessary for as much independence as possible in his self-care areas. He is not receiving any needed community-based services like DH or ILS. The lack of habilitative therapies poses a threat to the maintenance of his current level of independence and self-determination. The staff at the facility are not provided with specific training in working with people with IDD and there is limited carry-over of the rehabilitative therapies he has received on an intermittent basis.

CB does not have a professionally appropriate individual service plan (ISP). It is not based upon a comprehensive functional assessment as described above. The plan is usually developed with only the service coordinator, one member of the nursing facility staff, and CB. Despite the fact that CB’s sister visits CB weekly, the service coordinator does not include her in the meetings or consult with her. There is minimal information in the ISP regarding his medical/nursing, clinical, dental, and nutritional needs. CB has only two outcomes: 1) he wants to be a resident volunteer and 2) he would like to continue residing in the nursing facility. The ISP is not a person-centered plan because the second goal is the same as two other individuals in the service coordinator's case load. Even the same questions are asked of each person at each visit: whether there have been any hospitalizations, falls, participation in activities, satisfaction with service coordination, and specialized services requested. Despite asking about hospitalizations, the quarterly notes of January 27, 2016 do not record that CB was hospitalized for kidney failure and discharged on January 21, 2016. The ISP does not include any individualized transition planning or discuss barriers to community living and Section 9 Phase II is blank. There is no description of what the community would look like for CB and necessary services and supports have not been identified. The ISP is not implemented consistent with CB's expressed wishes to receive ILS and DH services.

CB would benefit from living in an integrated setting in the community with appropriate supports and services. CB has involved family and yet they are not consulted or involved with the services provided by the LIDDA. The needs that CB presents are no different from people who are successfully served in the community. He could be served in a group home or host home setting. He is a very social individual who enjoys performing meaningful tasks at the facility and would benefit from a setting where his strengths would be recognized and his preferences honored.

CB has not made an informed choice to remain in the nursing facility. While the community living options (CLO) are offered to him at the required intervals, there is no individualized and experiential discussion with CB about what community living would be like for him. Instead, it is a routine review of the written materials and a checklist, presented in a manner that is difficult for CB to understand. The lack of historical information in the ISP, the lack of involvement of his sister by the service coordinator, and the lack of knowledge of the service coordinator and nursing facility staff regarding his previous residential experiences hampers their ability to understand him and what he knows and prefers about community living. At each CLO session, CB states that he wants to continue living at the nursing facility so that he can be close to his sister. However, it is not clear if this statement indicates that his primary wish is to be close to his sister, or if it is the nursing facility living experience that he is choosing. There is no exploration of the full meaning of this preference or any indication of discussion with his sister about the type of community living options that would meet their need for continued involvement with each other in a community setting.

Individual: DP

Waxahachie, Texas Review Date: August 25, 2017

DP is a forty-eight-year-old woman who lives at a nursing facility in Waxahachie, Texas. She was admitted to this nursing facility on December 19, 2005 when she was thirty-seven years old. The social services history in her record states that DP lived with her parents until their death and then was admitted to a facility. She is the youngest of six children. DP's brother is her guardian and with his wife, visits her, usually weekly. Her sister-in-law says that she has known DP since she was one year old. DP's sister-in-law thinks that DP went to school until the fourth or fifth grade. The record does not show whether or not she was ever employed or in a day program.

DP has Down syndrome, heart failure, diabetes requiring insulin daily, a mood disorder, dysphagia, and gait disturbance. She is ambulatory but uses a wheelchair for longer distances. DP requires some assistance with her activities of daily living. She has lived in the same room in the facility since her admission. I met with DP in her bedroom, which was filled with personal items including many books, stuffed animals, puppy pictures, and puzzle books. She does not have a roommate as her roommate recently died. DP spoke softly and said she liked to read and liked animals. She said she likes to go to the activities in the facility and would like to go out more.

DP did not receive a comprehensive functional assessment of all her habilitative areas that accurately identifies all her individual strengths and needs. She did not receive an assessment of her sensorimotor development, her affective development, auditory functioning, cognitive development, social development, adaptive behaviors, and vocational skills. She had a PASRR Level 1 done on January 31, 2017, due to a change in ownership of the nursing facility. She had a PASRR Evaluation (PE) done on October 30, 2013, eight years after her admission to this facility, and again on May 2, 2017. Both PEs are positive for intellectual and developmental disabilities (IDD) and mental illness (MI). She has also received MDS reviews for nursing and medical issues on September 15, 2016; December 2, 2016; and May 16, 2017, conducted by the same registered nurse. She has nursing care plans, developed by the nursing staff and reviewing her medical/nursing concerns. The records show her first therapy evaluation was on June 24, 2016 and she had a psychiatry evaluation on March 21, 2017. Despite her diagnosis of dysphagia, she did not have a speech therapy evaluation until March, 2017, although she did have a modified barium swallow study (MBSS) on January 2, 2013 and again in March 2017. These evaluations all take place at varying points in time during her twelve year stay at the facility and capture information over a very wide span of time.

DP is not receiving all necessary specialized services. She is not receiving any nursing facility specialized services although she needs OT (occupational therapy), PT (physical therapy), and ST (speech therapy). The PE of May 2, 2017 recommends Alternative Placement Services, Service Coordination, and Occupational Therapy. At each of her quarterly service planning team meetings (SPT), the service coordinator stated that "Ms. Parks made no indication that she was interested in any additional services" and no specialized services are necessary. The only attendees at these meetings are DP, one member from the facility, and the service coordinator. After twelve years in the facility without any therapy, she finally began receiving rehabilitative OT in February 2017, PT in February 2017, and ST in March 2017. However, none of these services are habilitative and all are intermittent and time-limited. Each of these therapies afforded her some improvement in her skills. For example, prior to starting PT, DP could only ambulate for twenty feet; at the evaluation in May, after receiving some limited PT, she could ambulate one hundred and twenty-five feet. DP also gained functional abilities in transfers, going from needing caregiver assistance to needing only stand-by assistance. She went from standing balance of ten minutes to standing balance of twenty to twenty-five minutes. DP has also improved her swallowing with speech therapy and should continue to receive ST. While her most recent swallow study of March 2, 2017 does not show any signs and symptoms of aspiration, she has a diagnosis of dysphagia so it is very important that this condition be monitored closely. Clearly, she has benefitted from the increased emphasis on her functional abilities. She should have been receiving these therapies a decade earlier and on a consistent basis so that she would not have lost so many skills. Unfortunately, since these therapies are all time-limited, they have all ended and she is no longer receiving OT, PT, or ST. To avoid losing her skills, DP should continue to receive OT, PT, and ST on an ongoing basis as habilitative services, and not through the time limited rehabilitative services.

DP is not receiving any LIDDA specialized services except for service coordination, although she could benefit from these specialized services including behavior supports, Independent Living Skills (ILS), Day Habilitation (DH), and alternative placement services. DP had a psychiatric evaluation and review of her psychotropic medication, Zoloft in March, June, and August, 2017. DP has not been provided with behavioral supports even though she would also benefit from these services. DP would also benefit from regular counseling sessions in order for her care providers and family to determine whether or not she is expressing to do harm to herself. Her roommate has recently died and she would benefit from grief counseling.

DP likes to be active in the nursing facility and has very little opportunity to be part of the community; she should be receiving ILS and also be presented with an opportunity to visit DH programs to see if she would like to participate in a more stimulating environment, including the chance to earn some money. She has been in the nursing facility for twelve years and has not experienced any of these opportunities. While she cannot recover the past, she is still young enough and healthy enough to enjoy a more active life, going outside the segregated confines of a nursing home.

DP is not receiving a program of continuous active treatment, consistently implemented. With the exception of service coordination, she is not receiving the necessary specialized services and shows a decline in her functional abilities, as referenced above. The nursing facility staff do not receive specialized training in working with individuals with IDD and there is no carryover from her intermittent therapy sessions to other settings. She has not received the services which would enable her to acquire the behaviors necessary for her to function with as much self-determination and independence as possible. She rarely leaves the nursing facility and has limited socialization opportunities. Other people with Down syndrome who are similar to DP are working in grocery stores, going to dances, dating, attending book groups, or involved in other learning opportunities. With the continued lack of therapies and specialized services, DP will continue to lose functional abilities and will not enjoy the level of independence of which she is capable.

DP does not have a professionally appropriate Individual Service Plan (ISP). The plan is usually developed with only the service coordinator, one person from the nursing facility, and DP. The service coordinator has never spoken with DP's family despite the fact that they visit her each week and that her brother is her legal guardian. In fact, the service coordinator was unaware that DP's brother was her guardian until the day before I met with DP. Additionally, no one from the therapy departments attends or is consulted. Despite her diagnoses of dysphagia, heart failure, and mood disorder, there is very limited information presented under the areas of clinical, medical, adaptive aid, or nutrition. The information frequently consists of just one sentence and does not provide a comprehensive picture of who DP is and what her strengths, preferences, and needs are. There are only two outcomes for her to achieve: 1) to continue to reside in the nursing facility; and 2) to participate in social activities so she can continue to interact with her friends. These outcomes are very limiting and not ones that will encourage the acquisition of skills or increase her independence. There are no goals presented that would enable DP to interact outside of the nursing facility. DP's needs can be met outside of the nursing facility and yet there is no transition plan, no barriers identified, and no problem solving to reduce barriers. Section 9 phase II of her ISP is not filled out so there is no individualized description of what the community might look like for DP. The ISP is not a person-centered plan for DP because there is no discussion of her past history, very little information about who she is and what she likes and dislikes, and no recognition that her needs could be met in the community. Some of the same language that is in DP's ISP also is found in the ISP of another individual seen during this review.

DP would benefit from living in an integrated setting with appropriate community services and supports. She is very similar to many other people with Down syndrome who successfully live in either group homes or host homes. Her health needs are no greater than others who live in the community with appropriate nursing support. While she has a diagnosis of heart failure, she is not receiving any treatment for it and is not followed by a cardiologist as she would be if she lived in the community. DP would be much more active and could participate in a full, rich social life. She is young enough to have many fulfilling years of life left to her and living in a nursing home, with people who are much older than she is, is not the appropriate setting for her.

Neither DP nor her guardian made an informed choice for her to remain in the nursing facility. While the community living options (CLO) are offered to her at the appropriate six-month intervals, there is no experiential discussion with DP about what living in the community might mean to her. She has never been offered visits to community programs, opportunities to explore community activities, or even brief community experiences. The limited information provided to her is not tailored to her cognitive abilities, does not provide choices that she can understand, and, most importantly, is not designed to engage her in a conversation about community living. Because she has spent nearly all her time in the nursing home for the past twelve years, she has very little experiential knowledge to compare with her current setting. At each CLO session, the service coordinator simply states that she wants to remain in the nursing facility. This places an affirmative action on the part of DP, who has very little recent community experiences, who stopped going to school when she was only ten or twelve, and who has not been given any experiences of being in the community.

There is no indication that her service coordinator has engaged her or her guardian in a conversation focusing on DP's preferences, strengths, and interests and how they might be served in the community. Even though DP's brother and his wife have remained involved, and he is her legal guardian, the service coordinator stated that he has never spoken to them, and has never presented them information regarding community living options or specialized services. Despite the fact that DP spent all of her childhood and young adulthood living with her family, the death of her parents has consigned her to spend the rest of her life in a nursing facility.

Individual: SB

Elgin, Texas Review Date: August 16, 2017

SB is a 53-year-old woman who has resided at a nursing facility in Elgin, Texas since February 14, 2008. SB was very engaged in talking with me and was articulate and thorough in her responses to questions. Prior to coming to the nursing facility in 2008, SB lived at home with her parents "until her mental illness was too much for them," when she was in her early twenties. After that she said she "just let the State put me where they wanted because I had no choice." Although the MDS screening states that she came from another nursing facility, the service coordinator thought she lived in supported living apartments funded through the mental health system, and attended a psychosocial workshop, which SB stated was the Johnson City Day Care Center. The service coordinator stated that there was no medical reason for SB's admission to the nursing facility; instead, she was admitted primarily because she could not take care of herself.

SB's mother died seven years ago and her father has been deceased for some time. She has a brother but he does not visit and she apparently has no other family. She has a friend who comes and visits her frequently. SB has diagnoses of hypothyroidism, an unspecified intellectual disability, schizophrenia, and acquired nephrogenic diabetes insipidus.

SB began dialysis on June 18, 2016 for end stage renal disease, and now attends three times a week. She has to wake up at 2:30 am, leave the facility at 4:00 am, and not return until 10:30 am. These days are tiring, resulting in SB remaining in her room for the rest of the day. The nursing facility staff report that she has become more active since she began dialysis. On the days when she doesn't have dialysis, she likes to participate in the activities at the nursing facility and, even more, to leave the facility to participate in community events. She likes to color and paint and showed me a number of coloring pages that she had posted on her walls. She loves to go bowling once or twice a month, and was excited about going to the Dollar Tree later that day, although she feels the indignity of having to go with staff "leading her around by the nose." She also expressed fear of all the people who come and go in the facility, and occasionally experiences both visual and auditory hallucinations. Staff at the nursing facility confirmed her fears, but also said that she has become more active since she has dialysis on a regular basis and has improved considerably in the past few months.

SB did not have a comprehensive functional assessment of all habilitative areas that accurately identifies all her strengths and needs. She did not have assessments in the areas of sensorimotor development, affective development, cognitive development, social development, adaptive behaviors, or vocational skills. She had a Diagnostic Review on October 2, 2015, which confirms ID but states that her IQ is 0. She had a PASRR Evaluation (PE) on April 14, 2015, which recommends only service coordination. There were no other PEs or PASRR Level 1 documents in the records I reviewed. SB had her a physical therapy (PT) evaluation in September 2016, and a behavioral health evaluation in September 2016. Multiple MDS evaluations were conducted in 2014, 2015, 2016, and 2017. Nutritional assessments associated with SB's dialysis care have also been regularly done. These assessments occurred over a wide range of time, though, and did not present a comprehensive picture of SB's strengths, needs, and preferences at any given point in time. They were also not done as part of a collaborative process by an interdisciplinary team of professionals.

SB is not receiving all necessary specialized services. She is not receiving any LIDDA specialized services other than service coordination. She eventually was recommended for Independent Living Skills (ILS) at her August 2, 2017 service planning team (SPT) meeting, but it had not yet begun because the LIDDA had not yet identified an ILS provider. She would have benefitted from ILS over the last several years, as she enjoys being active, engaged, and involved in community activities, including the local library. ILS would enable her to access the community more frequently than she does with only facility trips, and allow her to develop and maintain skills. She also would benefit from a day habilitation program (DH), which she indicated at her SPT meeting of August 2, 2017 might interest her. Unfortunately, the service coordinator has not arranged any visits to DH providers, and the LIDDA has only contracted with one local day habilitation provider to offer that service. She should be assessed for vocational services as she is relatively young, and should have the opportunity to determine if there is work that she would enjoy. It would also enable her to earn some money to supplement her minimal disability income. Oddly, the SPT meeting notes state that she has declined all specialized services, even though she is receiving service coordination, requested and was recommended for ILS, and some therapy.

SB currently is receiving no nursing facility specialized services even though she would benefit from both habilitative PT and OT to maintain mobility and acquire ADLs. She received episodic physical therapy (PT), through PASRR in May to July 2015, and again in April, May, and July to mid-September 2016 to assist with bed mobility, functional transfers, safety and ambulation. She had occupational therapy (OT) from August to October 2016, through PASRR, where she worked on grooming, toileting, and functional mobility. She made progress in her goals and was discharged to Restorative Nursing Program (RNP), which apparently ended in 2016. It is not clear why these therapies were intermittent and had breaks in service, since her needs, goals, and interventions did not change. She should have continued without interruption so that she would not have lost skills, as documented in her PT assessment of July 2016, which stated that previously she was able to ambulate with her walker and was not dependent upon a wheelchair. A 2015 assessment states that her previous level of walking was “unlimited,” but had deteriorated to only 200 feet. SB expressed a clear desire for PT saying “I need that to keep my legs strong.” She also receives psychiatric services through the nursing facility monthly, including review of her psychotropic medications and their side effects.

SB is not receiving a program of continuous active treatment, consistently implemented. She did not receive a comprehensive functional assessment to form the basis of her specialized services. She is not receiving all of the specialized services that would help acquire and maintain skills related to independence and self-determination. Due to the intermittent nature of her limited specialized therapy services and the absence of virtually all LIDDA specialized services, SB loses skills in between therapy sessions. Her preferences are not recognized, in that she expresses a need for physical therapy and would like to visit day habilitation programs. While she has received restorative nursing programs to maintain her PT skills, there is not carry-over from staff trained in her OT program. The facility does not provide training to the staff specific to working with individuals with IDD. Her services do not focus on providing her with the services that will increase her independence and prevent regression of the skills she has. A pattern of skill loss has already developed, as outlined in the PT and OT assessments of 2015 and 2016.

SB does not have a person-centered Individual Service Plan (ISP) that is appropriate to her developmental strengths, preferences, needs, and age. She has only two outcomes to achieve as outlined in her quarterly SPT meeting of August 2, 2017: 1) “I desire to maintain my current level of physical functioning" and 2) "I desire to maintain activities." Both of these goals reflect her preferences, but they do not describe specific activities or interventions to achieve these general goals. As a consequence, the quarterly meeting considers the goal met if she attends even one nursing facility activity and does not have any overall decline in her medical condition. These goals do not focus on specific actions, such as increasing muscle strength, balance or ability to walk distances, or recognize that her socialization needs far exceed activities provided only within the nursing facility or her expressed desire for ILS services. Interestingly, the ISP states that "[SB] desires to participate in specialized PT services" and that "helping out gives her something to do and makes her happy" and yet neither of these expressed desires have been followed up with consistent PASRR services of PT and ILS. Phase II of the transition section (9) of the ISP is blank, so there is no description of what community supports SB might need or desire, and no concrete description of what a community living arrangement might look like for SB.

SB would benefit from living in an integrated community setting with appropriate services and supports. SB has lived in the community previously, first with her parents and then in a supported living program, most likely through the mental health system. She stated to me that she would like to live in a group home but wonders if they will be able to manage her dialysis. Many people who receive dialysis are able to live at home independently, often for many years. SB's needs can be met in community programs with staff trained in working with people with IDD and oversight of her medical issues. She is similar to other people who are currently served in community programs. She is also much younger than most of the other residents of the nursing facility and would benefit from living with people in her age group.

SB has not made an informed choice to remain in the nursing facility. She has had multiple community living options (CLO) reviews at the prescribed intervals, and each of those reviews conclude that she wants to remain in the nursing facility. However, the SPT has not engaged in discussing with her the ways in which she could be supported in the community and how to overcome her perceived barriers to community living, such as how she would manage her dialysis. SB's planning and the education about community living provided to her have not been individualized to her specific needs and strengths. Despite this conclusion, SB stated to me that she would prefer to live in the community if her needs could be appropriately met. She has not had the opportunity to visit any community programs although her service coordinator stated that SB has looked at a slide show. The service coordinator said she didn't know how to arrange transportation to visit community programs. SB has been in the nursing facility for seven years, and has had very little opportunity to leave the facility, experience community life, or participate in community activities, even in the smallest of measures. Further, SB has not been presented individualized information about what the community might look like for her and how her needs and preferences could be met. Barriers to her successful placement are not elicited and there is no problem solving around reducing barriers. The service coordinator stated that SB has expressed a fear that the facility will get "mad" at SB if she participates in community options, and won't let her stay. SB's mental illness can also be successfully managed in the community; a thorough discussion by her SPT, with an opportunity to experience the community through ILS and day habilitation would help her make an informed choice.

Individual: DH

Bastrop, Texas Review Date: August 15, 2017

DH is a 59-year-old gentleman who has resided at a nursing facility in Bastrop, Texas since February 29, 2016. When I met with him, he was lying in bed with the covers pulled up close to his face. He engaged with me by making eye contact and answered all questions asked by saying "yeah." The television was on to an older western. He did not appear to be focusing on it. DH is described as liking people and having rapport with certain staff. His mother lives in a nearby assisted living facility. She comes to visit several times a week and he enjoys her visits very much. His sister is his guardian and is involved in his care plan meetings and active in his life. DH has autism.

DH's admission to the nursing facility in February 2016 followed a hip fracture that occurred in November 2015. His hospitalization for the fracture was complicated by sepsis, a deep vein thrombosis (DVT), and a pulmonary embolism (PE). He entered hospice care on February 1, 2016 with a "terminal diagnosis of megacolon" and "unable to eat." He weighed 227 pounds. There is conflicting information about how long he was in hospice, but it appears that he remained in this status for the month of February 2016. Prior to his hip fracture he was living at home with his parents and received support through a HCS Waiver slot. He was very social, involved with his church, able to walk, and frequently went out to activities with his family.

DH has not received a comprehensive functional assessment of all his habilitative areas that identified his strengths, preferences, and needs. He has not received an assessment of his cognitive development, sensorimotor development, adaptive behaviors, and independent living skills. He had a PASRR Level 1 on February 29, 2016, which is positive for suspected IDD and mental illness. He then received a PASRR Evaluation on March 3, 2016, which confirmed an IDD but not mental illness. DH received a second PASRR Level 1 screening on November 30, 2016, and then a second PASRR Evaluation on March 2, 2017. All of these PASRR screenings and evaluations are positive for IDD. With the exception of the first Level I screening, all are negative for mental illness. However, DH has a diagnosis of schizophrenia in his records, but does not have indications of any symptoms characteristic of this illness. A thorough assessment would clarify if this is truly an illness that he experiences and not a label that he received at some point in time, perhaps due to his autistic behaviors. DH did receive a speech and language pathology assessment (SLP) on March 3, 2016, which evaluated both his problem-solving abilities and his dysphagia. It was determined that he does not require on-going speech therapy (ST). He had an occupational therapy evaluation (OT) on March 3, 2016 and a physical therapy evaluation (PT) on March 2, 2016. He had subsequent MDS assessments, as recently as August 8, 2017, and nursing care plans that detail his nursing diagnoses and their management. However, there is no single comprehensive assessment that brings together these various evaluations and screening tests and presents a cohesive picture of DH's needs and strengths.

DH has received some, but not all necessary nursing facility specialized services even though he could benefit from, and needs, these services to maximize functioning to avoid deterioration. DH did receive rehabilitative PT, on an intermittent basis from March through May in 2016. He also had rehabilitative PT for three months from July to August 2016, but that was again terminated because he demonstrated "marked improvement" and increased his right hip flexion to 60 degrees. His evaluation shows his right hip flexion is now 30 degrees, but with a month of therapy, it can return to 60 degrees. Despite this past improvement, his present limitations, and request from his family for more assistance, the physical therapist told me in my interview that he does not believe DH would benefit from additional therapy or a CMWC. The therapist also said that PASRR is very new and he acknowledged that he doesn't know much about it. DH received rehabilitative OT on an intermittent basis in May 2016. OT worked on standing balance, sit to stand transfer, and propelling his wheelchair for more than 100 feet.

DH would benefit from habilitative PT and OT services on an on-going, consistent basis. His skills have declined since his admission to the facility, sixteen months ago. When he was admitted he could do a stand-pivot transfer; today he is totally dependent upon staff for transfers with a Hoyer lift and uses a Geri-Chair which he cannot propel. Previously he could self-propel his wheelchair for more than 100 feet. He suffered a stage II wound on his right heel, possibly from the wheelchair, which lasted at least 122 days and required the services of a wound care doctor. At the time of his admission, DH's sister/guardian stated "that the most important reason she has DH in this NF is to get DH to where he can walk again…" That goal has only been intermittently worked on with little progress during the past 16 months.

The family has also asked for a CMWC. There was conflicting information regarding the CMWC that the family has requested. The physical therapist disagrees and states that DH requires a Geri-Chair so he won't slide down. The family would like the CMWC so he can go visit his mother. The physical therapist says that they can push him in the Geri-Chair over to his mother's apartment, but nursing staff reported that they cannot take the Geri-Chair out of the nursing facility. In addition, when I was in his room, there was a large, new wheelchair in his bathroom and the nursing staff said that the family had bought it for him, but it is not being used at all. There should not be this level of disagreement and confusion among members of the team regarding something as important as a wheelchair.

DH is receiving no LIDDA specialized services other than service coordination. There is also indication in the ISP meeting notes that the nursing facility does not notify the service coordinator of care plan meetings in a timely manner. Even though DH would benefit from, and has been referred for, Independent Living Skills and needs an evaluation for Day Habilitation, he is not receiving either specialized service. His family consistently requested ILS services, and wants DH to go on outings in the community. This is not occurring. DH has difficulty accessing even the activities in the facility since he cannot propel himself in his wheelchair any longer. The ILS services would enable him to access these activities. His family has become his only means of socialization. His primary activity seems to be watching television in his room. He should also be assessed for Day Habilitation as he once was active in the community. At the June 26, 2017 SPT meeting his sister requested ILS services, and a referral was made. However, at the time of my visit he was not receiving any of these services. Although the record is not clear, it appears that DH received behavioral support, first requested by the family in March 2016 and concluded by the November 2016 ISP meeting. It ended because he did not exhibit any behaviors. He did not receive any other PASRR services.

DH is not receiving a program of continuous active treatment of specialized services, consistently implemented. Other than service coordination, he is not receiving any specialized services. The staff of the facility do not receive training specific to caring for individuals with IDD. The team seems to be in disagreement about what services he needs, and the physical therapist is unwilling to use the wheelchair purchased by the family. DH has lost a significant amount of skills during the time he has resided in the nursing facility, deteriorating from being able to do a stand-pivot transfer and self-propel his wheelchair to needing a Hoyer lift for all transfers and a Geri-Chair when he is out of bed. His primary activity seems to be watching television in his room. The intermittent nature of his therapies has meant that he has spent far more time off of therapy than involved with therapy. During this time, he has lost skills in self-care, socialization and mobility. All of these deficits are worsening without needed services.

DH does not have a professionally appropriate, person-centered Individual Service Plan (ISP) that is based on his strengths, needs, and preferences and includes strategies for addressing barriers to community living. Instead, DH's most recent ISP of June 26, 2017 lists only two outcomes for him to achieve: 1) to strengthen, increase and maintain my level of physical functioning needed for all my ADLs; and 2) to watch television in my room. It is hard to see how the first goal can be achieved without receiving any physical or occupational therapy; the second goal requires no increase in skills to achieve and has no relation to DH's identified preferences. Further, DH's ISP does not accurately reflect his current situation, when it states "I like to walk on my own without the assistance of others" and "I desire to be independent." While these may have been his preferences at admission, he is far from achieving these goals and does not have a clear outline in his ISP for how he could possibly achieve them. Sitting in a Geri-Chair or watching television in his room will not enable him to achieve these preferences. Similarly, DH's ISP contains fundamental misunderstandings about DH's supports. For example, the ISP states that "I ambulate with a wheelchair" but doesn't outline that, because it is a Geri-Chair, he cannot ambulate unless someone else pushes him. Finally, the implementation of the ISP is not consistent with his expressed preferences and the goals of his guardian as stated on March 3, 2016: "the most important reason she has [DH] in this NF is to get [DH] back to where he can walk again … with improved health, strength, and mobility, she and [DH] will consider an HCS group home." The ISP of June 26, 2017 now states that his long-term plan is to remain at the nursing facility, even though DH's PE of March 2017 recommends alternate placement services.

DH would benefit from living in an integrated setting with appropriate community supports and services. Prior to his hip fracture in November 2015, he lived his entire life in the community. By all accounts, he was very active in the community before admission and enjoyed a variety of activities, including attending church and participating in activities with his parents. He was fairly independent in his self-care. He was admitted to the nursing facility to take advantage of therapies to recover from his hip fracture, but instead he has regressed from the skill levels he had at admission. Although DH's family maintains close ties to DH and visits him on a regular basis, DH would be able to see his family more frequently in a more integrated setting and have access to a broader array of activities.

DH and his sister, his guardian, have not made an informed choice to remain in the nursing facility. The goal at admission, as expressed by his sister was for him to gain strength and come back to live with the family or other community setting. However, there is no individualized description of what the community might look like for DH – information that should be detailed in Section 9 Phase 2 of DH's ISP but is not filled out – and his service coordinator has not had an individualized conversation focused on his preferences, strengths, and interests. There is also no indication that DH's service coordinator provided DH and his guardian opportunities to visit and experience options that aligned with DH's family's desire for him to live nearby and receive appropriate medical supports. His family has expressed that they would like him to become strong enough to return to living with either his family or a host home. His sister is currently considering a host home or living with family once she moves to the area. She wants him to gain strength but the therapist does not think he can benefit from therapy, so DH is caught in a continuing downward spiral that makes leaving the facility appear ever more unlikely. His skill areas are decreasing and the goal of gaining strength is less likely. As a result, DH and his guardian's preference for him to return to living at home will become ever more unattainable. There is no indication the efforts were taken to address barriers to the community.

Individual: LB

Austin, Texas Review Date: August 14, 2017

LB is a 74-year-old woman who resides at a nursing facility in Austin, Texas. She was admitted on January 5, 2016. She is her own guardian. When I met with her, she was sitting in the dining room/activities room. Although it was late morning, she had leftover food on her face. She was quiet, but responded to questions. She pointed to her leg and said that it still hurt.

The nursing facility staff report that she likes to paint and color and especially enjoys watching the Food Network. LB needs assistance with ADLs, except for feeding. She uses a wheelchair for mobility and is able to transfer with staff assistance. She is usually quiet, but is protective of her personal space and becomes upset if people invade her space. She does not leave the nursing facility for any activities. Her family is involved, visits weekly, and participates in her care plan meetings.

Prior to her admission to the nursing facility, LB lived at a group home. She was hospitalized on December 30, 2015 for lower GI bleeding and right elbow pain, swelling, and redness. The GI bleed was from hemorrhoids due to constipation. The elbow was treated with antibiotics and resolved. Although the hospitalization was for only 6 days, and her medical diagnoses at discharge was hemorrhoids, the group home determined it could not meet her needs and she was admitted to the nursing facility. She said that an uncle had moved her to the nursing facility and she did not know about moving back to her group home.

LB had a PASRR Level 1 screening on January 5, 2016 and a PASRR Evaluation (PE) on January 7, 2016. The PE recommends specialized services and indicates that she had a stage 2 wound (decubitus). Nursing facility notes show that the wound progressed in severity with a stage 4 wound on her buttocks and stage 3 wounds on her right hip and sacrum in November 2016.

LB does not have a comprehensive functional assessment of all habilitative areas that accurately identifies all her strengths and needs. She has not had assessments of her social development and adaptive behaviors, as recommended by the PE, or of her cognitive development and independent living skills. The nursing facility conducts the MDS and other nursing assessments such as fall risk, side rails, self-help skills, nutritional status, and similar medically based assessments. She had evaluations by occupational therapy (OT), physical therapy (PT), speech therapy (ST), psychology, and psychiatry within the first month of her admission.

LB is not receiving all necessary LIDDA specialized services and no nursing facility specialized services, even though she could benefit from and needs these services to maximize functioning and avoid deterioration. The PE of January 7, 2016 recommends nursing facility specialized services of durable medical equipment (DME), and ongoing habilitative PT, OT, and ST. It recommends LIDAA specialized services of service coordination and alternate placement.

LB received intermittent OT, first from January 6, 2016 until March 25, 2016, then again for a month (June 8, 2016 – July 31, 2016), then again for another month (March 6, 2017 – April 1, 2017), and then again on May 25, 2017. The pattern is similar for PT, with intermittent services from January 2016 until March 2016, again in October 2016, December 2016, and April 2017 until July 2017. ST was provided for a month from January until February 2016. All these services were time-limited and intermittent rehabilitative services, and not long-term habilitative services provided through PASRR. The intermittency of these services is unnecessary. Habilitative PASRR specialized services can be approved for a six-month period, if requested, and can be renewed repeatedly for additional six-month periods. There is no need for constant interruptions, with the subsequent loss of skills. This is particularly disturbing since her sisters “felt it would be best for her to be in a NF to return [LB] back to baseline and have her be more independent and back to walking again.”

LB also received intermittent behavioral health services, on a monthly basis from January 2016 until July 2017, again not apparently through the IDD PASRR program. She had several sessions with a behavioral analyst for her behavior outbursts, but the plan does not indicate the positive replacement behaviors or the antecedents. The recommendation to staff is to ignore her screams and then redirect when she is quiet. She has a customized manual wheelchair (CMWC) which she received in December 2016, nearly a year after admission and only after she developed serious wounds. She received a PT referral in October 2016, with a note that she has been “referred to PT secondary to wound from current sitting system.”

LB enjoys the activities at the nursing facility and would benefit from the additional attention and skill development afforded by Independent Living Skills (ILS) either within the facility or in the community. She has not been assessed for Day Hab, even though she might also enjoy that service, and would benefit from the additional skill development and socialization.

LB is not receiving a program of continuous active treatment of specialized services, consistently implemented across settings. As noted above, she has not received habilitative therapies, but instead only was provided intermittent interventions, with months or weeks between sessions, even though she showed improvement over time with each skill. If she had continued with PT and received her CMWC much earlier, she might have avoided deteriorating wounds and the aggressive care she later needed. Even though she continues to have behavioral outbursts, she does not receive behavioral therapy, only monthly counseling sessions. Further, nursing assistants are not trained to provide habilitative care for people with IDD. LB’s intermittent therapy sessions are not integrated into her daily care by the nursing assistants. She is not receiving any services outside of the nursing facility although she enjoys community activities and likes to participate in programs outside of the nursing facility. She previously lived in the community but she is not working on skills to encourage independence and self-determination.

LB does not have a professionally appropriate, person-centered Individual Service Plan (ISP) that is based upon her strengths, needs and preferences and includes strategies for addressing barriers to community living. Her most recent ISP lists three current goals: 1) [LB] would like a say in her care; 2) [LB] would like to get her hair done monthly and play bingo; 3) [LB] would like to keep her dentures clean. The first goal is an expression of her basic rights as a NF resident and not a goal for her to achieve – as is goal 3. Her second goal does not provide her with specific skill development which would increase her independence. The goal could be written so that LB could learn to make her monthly hair appointment and attend a community bingo event to increase her socialization skills. Despite her sisters’ statement that they want her to “return to baseline,” “be more independent,” and “back to walking again”: the goal of “[LB] will increase her independence and by being more mobile” has been discontinued as of June 14, 2017. Despite this stated objective and years of living in the community, the ISP states that LB wants to remain in the NF.

LB would benefit from living in an integrated, community setting with appropriate supports and services. She previously lived in a group home, participated in community activities, and benefited from community interactions. Her hospitalization was for hemorrhoids – a common condition in a person her age – which should have been brief and allowed her to return to her home in the community. She was admitted to the nursing facility for rehabilitation and her PE recommended prompt alternate placement as one of her specialized services. Nevertheless, her ISP, Sec. 9, Phase II concerning potential community living arrangements is left blank and there is no description or exploration of community options for LB. It appears that no further efforts were made to determine what supports she would need to return to the community or to identify and address barriers to her prompt return home. Instead, the default quickly became to remain in a long-term care facility, despite the original assessment, past history, and benefit she would receive from increased access to community interactions. The lack of specialized services has caused her to lose skills, to suffer serious wounds, and to make returning to the community a more difficult goal.

LB has not made an informed choice to remain in the nursing facility. She is her own guardian, and when I asked about moving back to the community she indicated she would consider it. The nursing facility staff believe she could live in the community with the appropriate supports, which she did just prior to her 6-day hospitalization. Her family would like her to remain in the nursing facility and it appears that their wishes are the ones being implemented. Section 9, Phase I of the ISP lists two barriers, both of which state that she does not have support from family members to live in the community due to her history in a previous group home. It also states that the sisters are open to tour HCS homes in South Austin, but there is no evidence that there is any plan developed to pursue this interest. Her service coordinator did not engage in an individualized assessment of strengths, needs, and preferences to provide information about what community living would look like for LB. CLO materials have not been presented in a manner tailored to her cognitive abilities, do not provide choices she can understand, and most importantly, are not designed to engage her in a conversation about community living. Further, LB has not been offered opportunities to visit community programs, participate in community activities, or explore community living arrangements. There is no evidence that barriers to the community – including her family's concerns– have been addressed. It is a sad commentary that becoming constipated and having bleeding from rectal hemorrhoids has consigned LB to a long-term nursing facility placement, possibly for the rest of her life.

Individual: SE

Itasca, Texas Review Date: August 24, 2017

SE is a forty-eight-year-old woman who was admitted to a nursing facility in Itasca, Texas on January 17, 2017. Prior to her admission to this nursing facility, SE was hospitalized on the psychiatric unit in Tyler, Texas, where her family is located. Although she has not had any contact with her family since her admission to the nursing facility, she speaks frequently of going home to live with her mother and also mentions having a sister and a son. SE is legally competent to make decisions. SE's emergency contact is her sister, JB, whose address is unknown.

SE is confined to a cramped, locked unit of the facility because she has been determined to be in danger of elopement and wandering. She does not ever leave the locked unit, although there is a small fenced area outside for smoking. I spoke with SE in the dining area of the unit. She said she would like to go for a ride in a U-Haul and would like to be anywhere but "here". She said she wants to go home to Tyler, Texas and to be with her momma. After a few minutes, she got up and left. I observed her a few moments later talking on a disconnected telephone by the nurses' station. The facility staff stated that she will often speak on that phone, as though she is in a conversation. She is very motivated by soda. The NF staff stated that there has been an increase in SE's behavioral problems since the time that she was admitted to the NF, although the staff report that she can be redirected. SE can be verbally aggressive and sometimes thinks that the staff is out to get her and holding her against her will. She refuses to sign nearly all documents but is compliant with her medications. She is described as pleasant and optimistic, caring about other folks and motivated to seek PASRR services. She has a strong faith. Staff report that she can also be pleasant and cooperative. She responded quickly to requests from the nurse on duty and interacted with her in a pleasant manner.

SE's PASRR Evaluations (PE) state that she has had more than one psychiatric hospitalization in the past two years. She has a diagnosis of schizophrenia and there is some question of a past history of drug abuse. Her records do not indicate where or how she was living prior to the psychiatric hospitalization. She is unable to provide information other than saying she wants to go home to Tyler and her mother.

SE did not have a comprehensive functional assessment of all her habilitative areas that identify her strengths and needs. She has not had assessments of her nutritional status, self-help development, sensorimotor development, auditory functioning, cognitive development, social skills, adaptive behaviors, independent living skills, or vocational skills. Her initial PASRR Level 1 screening of January 19, 2017 is positive for mental illness and IDD. She had PEs on 1/23/17, 1/29/17, and 5/10/17. The first PE is positive for mental illness but not IDD; the next PE on January 29, 2017 is positive for both mental illness and IDD. Despite her diagnosis of schizophrenia, she has not had a psychiatric or psychological assessment. She has an Interim Plan of Nursing Care that lists "monitor behavior and verbal outbursts" and directs assessments in other areas such as hydration, dental care and nutrition. She did not have any MDS evaluations in the records I reviewed.

SE had a therapy screening on January 18, 2017, and evaluations for physical therapy (PT), occupational therapy (OT), and speech therapy (ST), were all recommended. It is not clear from the records if or when they were provided. She also had a screening for these therapies on April 17, 2017 but appears to have refused this treatment.

SE is not receiving all of the specialized services that she needs. SE's PE dated January 29, 2017 recommended that she receive specialized services including alternate placement, service coordination (SC), and Independent Living Skills (ILS). The Interdisciplinary Team (IDT) met on February 2, 2017 and recommended that SE receive specialized services including OT, PT, SC, ILS, and alternate placement. The PE of May 10, 2017 recommends alternate placement, SC, OT, ILS, and mental health services. Because SE has a dual diagnosis of mental illness and intellectual disabilities, she is eligible for PASRR services through both the mental health and IDD divisions of her local LIDDA/LMHA.

After several refusals, SE began accepting mental health case management and ILS services in May 2017. She has received mental health case management services, from a male case manager, but has not received ILS services. SE's IDD service coordinator regularly attempts to visit SE, but she refuses to see him. Her refusals are based on the erroneous belief that he is someone that she has met in the past from the "Blood Bank" or the FBI with whom she had a bad experience. Although SE is more willing to accept services from women, and appeared comfortable talking with us, the LIDDA has not assigned her a female service coordinator because, as SE's IDD service coordinator explained, the LIDDA was not able to assign her another IDD service coordinator due to the LIDDA's limited resources. The mental health case manager stated that he does not attend any of SE's IDT meetings at the NF.

SE is not receiving any necessary NF or LIDDA specialized services other than Mental Health Service Coordination. She has refused all therapies with the possible exception of OT at the beginning of her stay. However, her refusals to accept services appear to be tied to her strong desire to return home and leave the facility. Significantly, she has not been provided with any behavioral supports or psychiatric oversight, which are fundamental to working with her and understanding the impact of her schizophrenia and/or possible drug use on her mental functioning. Without skilled intervention from a mental health clinician, it will be very difficult for her to develop the skills and behaviors that she needs to return to the community, a desire that is stronger than anything else in her life.

SE is not receiving a program of continuous active treatment consistently implemented. She is not receiving the necessary specialized services that will help her acquire the behaviors necessary for her to function with as much self-determination and independence as possible. She spends all of her time on a locked unit that the nursing facility staff say has very little activities. The minimal services she is willing to accept, ILS, is not provided. She spends her day wandering the unit, talking on a disconnected phone, eating, sleeping, and taking smoke breaks.

Because she refuses to meet with her service coordinator, there are no ISPs for SE on file.

SE would benefit from living in an integrated setting with appropriate supports. All of her PE's state that one of her specialized services is Alternate Placement. Nevertheless, there has been no serious effort to identify a community program for her, and no transition plan developed to assist her to leave the nursing facility. She has repeatedly voiced her desire to return home. SE previously lived in the community although the circumstances are not clear. She would need twenty-four-hour supervision and mental health services to successfully return to the community, like many other individuals with psychiatric needs who are served in the community with supports. The lack of skilled mental health services is the major barrier to her return. Without it, she will possibly continue to refuse the very services that will enable her to live successfully in the community. SE's IDD service coordinator informed me that if SE would agree to talk to him, he could probably find an IDD community placement for her.

SE has consistently stated from the time of her admission, and at every meeting since then, that she wants to return to Tyler, Texas. While it may not be realistic for her to return to her mother, community living is a realistic goal for her. When she states that she is being held against her will, she is accurate as she is on a locked unit. She has refused to meet with the service coordinator and does not understand her options or the specific actions needed to leave the nursing facility. Potential barriers to the community have not been identified and individualized community options have not been presented. Without the skilled mental health intervention she needs, she will continue to express a desire to leave and it will become ever more remote.

Individual: AH

Bastrop, Texas Review Date: August 15, 2017

AH is an 82-year-old woman who resides at a nursing facility in Bastrop, Texas. She has a mild intellectual disability. On the day I met with her, she was stylishly dressed with a flowery headband in her hair. She uses a wheelchair for mobility. She was very articulate in answering my questions. She had clear opinions regarding her preferences, likes, and dislikes and had little difficulty expressing them to me. She loves B.B. King and gospel music, used to sing in choirs and public events, and enjoyed dancing when she was younger. She regularly attends activities at the facility, particularly Bible study and bingo but desires more opportunities to leave the nursing facility and participate in the community. She stated, “I just stay home all day. That’s no good.” The nursing facility staff said she frequently sits by the front door and sings gospel music for everyone to hear. She entertained me with several gospel songs from her repertoire.

AH was admitted to the nursing facility on June 6, 2014 from an acute care hospital. Her admission was triggered by several falls. For many years, she lived by herself, and had what she describes as a “good life.” Her sister lived nearby and would cook for her. At some point, AH moved in with her sister who cared for her. Her sister’s health began to deteriorate around the time of AH’s hospitalization, so AH was not able to return to her sister’s home when she left the hospital. Shortly after AH was admitted to the nursing facility, she returned to the hospital and had a pacemaker implanted for atrial fibrillation. She also has an enlarged heart, diabetes, depression, and schizophrenia. She has knee contractures and needs to use a wheelchair. Her sister continues to visit her three times a week.

AH did not have a comprehensive functional assessment of all her habilitative areas that identified her strengths, preferences, and needs. AH has never received assessments that evaluated her needs in the areas of sensorimotor development, affective development, speech and language development, cognitive development, social development, and adaptive behaviors. She was not even identified as having IDD or a mental illness for almost a year after she was admitted to the nursing facility, despite her history of ID during her school years, her history of receiving HCS Waiver services, and her diagnosis of schizophrenia. The PASRR Level 1 screening, dated June 26, 2014, was negative for MI, ID, and DD. It was not until the PASRR Evaluation (PE) was finally completed almost a year later, on April 28, 2015, that she is identified as having ID. That PE does not list any contacts or family, despite the weekly involvement of her sister. AH received some nursing assessments through the MDS process and the nursing facility care plans but several of the MDS assessments in AH’s records were unsigned and incomplete. Other assessments were done by a physical therapist or an occupational therapist, but not in collaboration with other treatment team members and typically after significant events such as AH’s return from her second hospitalization for the pacemaker, not as part of her ongoing treatment plan.

AH is not receiving all necessary nursing facility and LIDDA specialized services, even though she could benefit from, and needs, these services to maximize functioning and avoid deterioration. She did not receive any specialized services for the first year she was in the nursing facility, due to the fact that she was not identified as having ID. AH now receives no LIDDA specialized services other than service coordination and has not consistently received any nursing facility specialized services, despite the recommendation of PT, OT, and DME in her PE. In her PE of April 28, 2015, she was recommended for community placement, but there is no evidence of any activity or effort to transition her to the community. The most recent PE, dated June 14, 2017, again recommends alternate placement, as well as nursing facility specialized services of OT, PT, and DME. Once again, there is no evidence of any efforts to transition AH or even identify specific transition services that she might need to move to the community.

AH received habilitative OT and PT from October 2016 until January 2017. She received time-limited OT and PT intermittently from January 2017 through mid-April 2017 and from late July 2017 to early September 2017. She also received time-limited PT for two months from January to March 2016; time-limited OT for one month from January to February 2016; time-limited PT for three months from February to May 2015; time-limited OT for two months from June to August of 2015; and PT and OT in July of 2014. AH would benefit from ongoing habilitative PT and OT, so that her services are not interrupted, delayed, and intermittently terminated. In the PT notes of January 2016, the therapist states that there has been "an increase in generalized weakness" and the OT acknowledges that there is a decline in upper body dressing skills. Nevertheless, AH has had only one period, from October 2016 until January 2017, when she consistently received habilitative PT and OT services. AH received a speech therapy (ST) evaluation in June 2015, which states that she does not require ongoing ST.

AH began receiving LIDDA specialized services, through Independent Living Skills (ILS) in February 2017, two times a month for two hours each. However, it appears this service was terminated because, as the service coordinator indicated, it is difficult for find ILS staff and providers. AH has indicated that she would very much like to be more active, would like to leave the nursing facility to go to church or attend community outings, and expressed an interest in Day Habilitation. The nursing facility staff stated that she would probably enjoy and benefit from Day Habilitation – a service AH received regularly in the community before her nursing facility admission. The records also indicate that a CMWC is "in process," as of November 2016, yet it still had not been delivered, and the order was discontinued in May 2017, when a "better facility chair" was substituted. There is no reason given for why she would not benefit from a CMWC, especially since she propels her chair herself and a lighter, personalized chair would be more clinically appropriate. The record also indicates that both AH and her sister requested a CMWC because her current chair shows evidence of wear. At the November 2016 treatment planning meeting, her sister expressed concern about the number of psychotropic medications that AH receives, at the time of admission to the facility she was taking only an antidepressant.

AH is not receiving a program of continuous active treatment of specialized services, consistently implemented across settings. She does not consistently receive PT and OT services, both of which would increase her abilities in the areas of mobility, balance, muscle strength and independence in activities of daily living skills (ADL), such as upper body dressing and hygiene. She consistently has stated that she wants to walk again and wants to be stronger. She has declined between the intermittent sessions of PT that she has received. Now, AH cannot consistently access the community on outings or spiritual events, such as church, even though she has expressly indicated a desire to continue her practice of going to church and singing in the choir. She has inconsistently received ILS services and not had the opportunity to increase her skills in self-determination and independence. The facility staff are not trained on working with people with IDD, and there is not the carry-over from therapy settings into other parts of her daily life.

AH does not have a professionally appropriate, person-centered individual service plan (ISP) that is based on her strengths, needs, and preferences and includes strategies for addressing barriers to community living. Her initial ISP was done on May 27, 2015, nearly a year after her admission to the facility in June 2014. She has only one outcome in her current ISP, dated May 10, 2017: "engage in a variety of activities beyond those provided by the nursing facility." Previously she also had the outcome of "maintain her best level of physical functioning," but that was discontinued at the most recent service planning team (SPT) meeting. It is unclear why this goal is no longer considered important, since she stated at my interview that she wants to have therapy so she can "get out of the wheelchair." For her entire stay at the nursing facility, these have been the only two outcomes that have been included in her service plan. She is not working on goals that would increase her independence or assist her to return to the community, both of which she stated she would like to achieve. While the meetings routinely include her sister, they do not recognize her requests, such as for a CMWC or an evaluation of the number of psychotropic medications AH receives. Despite AH's desire to return to the community, the ISP does not mention this goal, but instead states that she wants to stay at the facility and requires the "safe, comfortable, and secure environment" of the facility.

AH's ISP also does not include an individualized description of what community services could meet her needs, and specifically, Section 9, Phase II of her ISP – where this information should be provided – is left blank. Moreover, despite the stated goal of engaging in a variety of activities beyond those provided by the nursing facility, AH does not go out of the facility more than monthly, only receives ILS intermittently, and possibly not at all. Therefore, her single goal – a goal that is critical to informing AH about community options and allowing her to explore community alternatives – is not being consistently implemented, if at all. AH is a very active, lively woman and could be engaged in many more activities. She is described as being "independent," yet her ISP does not provide for growth in independence and self-determination, or provide a plan for helping her to achieve the meager stated goal. She is not receiving the very therapies that would address the reason she came to the facility in the first place: frequent falls at home. Despite having a single outcome in her ISP related to gaining skills in independent living, AH is not consistently receiving those services.

AH would benefit from living in the community. AH lived nearly her entire life in the community, up until her admission to the nursing facility in 2014. She lived independently and with her sister. Her sister, as recently as February 2017, inquired about her being able to come home and live with her. AH's records also indicate that alternate placement services were recommended in AH's PE in June 2017. In a more integrated setting, AH would have improved opportunities to achieve the primary goal identified in her ISP. She would also have access to the types of activities she cares most about – including church attendance and choir singing. In the nursing facility, AH's sister repeatedly advocates for her and for improved services, but those services, such as a CMWC, are not incorporated into her service plan or not provided. While she has some medical conditions that require on-going monitoring, such as her diabetes and heart condition, they are within the capacity of the community to address.

AH clearly indicated that her preference is to return home. Despite this stated preference, her ISP and the Community Living Options (CLO) documentation for the past year repeatedly indicate that she wants to remain in the nursing facility. Although CLOs occurred at mandated intervals, the limited information provided to her is not tailored to her cognitive abilities, does not provide choices that she can understand, and, most importantly, is not designed to engage her in a conversation about community living. It is also not designed to allow AH to experience what supports could be offered in the community and how those could meet her needs. Section 9 Phase 2 of her ISP is not filled out and neither her ISP nor the CLO process describes what the community would be like for AH, including where she might live, who she might live with, what she might do, and how her needs and preferences could be met. Contrary to the recommendations in her initial and subsequent PE, which indicate AH wants to live elsewhere and is interested in community-based programs, there has no effort to help AH return to the community. Her ISP states that barriers to living in the community are that she is familiar with the nursing facility, both she and her sister prefer her to live in the facility, and that there is not accessible housing available in the Bastrop community. This is in direct contradiction to AH's statements and to her sister's request to have her come and live with her, as documented in the SC notes of February 2017. AH's service coordinator recognized this contradiction in my conversation with him and admitted that the documentation inaccurately reflects AH's lack of interest in community placement. The plan to address these barriers is for the service coordinator to "review and discuss supports about group home and placement services," but there is nothing to indicate that this has happened or even what this means. The service coordinator stated that it is difficult to place people in rural counties and that he is unfamiliar with any host homes in the area, an option that AH has said she would consider.

AH has not made an informed decision to remain in the nursing facility, despite the multiple statements in the CLO section of the ISP. On the contrary, she has clearly stated that she wants to leave the nursing facility and return to living in a home environment, such as a host home. While it is true that she is 82 years old, she continues to yearn for an active life – one that includes gospel singing, church, bingo, being in her own place and able to get out into the community. She lived in the community her entire life and sees that as her desired home.

Individual: DP

Manchaca, Texas Date of Review: August 14, 2017

DP is a 75-year-old gentleman with a mild intellectual disability who has resided at a nursing facility in Manchaca, Texas since August 22, 2014. He loves the outdoors, enjoyed fishing with a volunteer who comes to the facility, and likes trips to the sports store, Cabela's, where he drives a powered cart around the store. In his room, DP has various photographs hung on the walls, but was particularly proud of one with him among a group of men in hunting clothes with rifles. He has a deer head mounted above his bed and he described how he had shot the deer. He is very articulate and engages easily with others. He said that he liked his roommate and prefers a roommate then living alone. He spends much of his day watching television in his room, preferring western movies and football games.

Prior to living in the nursing facility, DP lived at Marbridge Ranch for 57 years – the Ranch being another part of an enclosed campus serving people with IDD. DP was admitted to the Villa because of an overall decline in his health, functional level, and dementia. He is ambulatory and able to eat his meals in the dining room. He infrequently attends hygiene and exercise classes, which occur Monday through Friday in the facility. He often spends time in his room, especially since he lost his previous weekly Independent Living Skills (ILS) provider. His previous ILS provider frequently arrived late, and often not at all. DP gets up around 6 am and goes to the nurses' station to get his daily chewing tobacco, which he keeps until he goes to bed at 8 pm. The nurse who has worked with him for several years says he is alert and engaged, that his dementia is stable, and that he occasionally forgets or becomes agitated, especially when people are late.

DP has not received a comprehensive assessment conducted by an interdisciplinary team of professionals who are experienced in working with individuals with IDD. He did not have an assessment of his sensorimotor development, affective development, speech and language, social development or adaptive behaviors. He received a PASRR Evaluation on June 25, 2014 that shows he is eligible for specialized services but only recommended service coordination. There were numerous nursing facility assessments completed, regarding skin integrity, fall risk, contractures, pain, restraints, dehydration and malnutrition. Within two months after his admission to the Villa, DP received occupational therapy (OT) and physical therapy (PT) evaluations. However, the evaluations were not part of a collaborative planning effort to identify his specific developmental strengths and needs. He later received a PT assessment as a result of shoulder pain, as noted in his August 2016 service planning team (SPT) meeting. But none of these evaluations, taken separately or together, present a comprehensive statement of DP's needs and strengths.

DP is not receiving all necessary specialized services, even though he could benefit from and needs these services to maximize functioning and avoid deterioration. He receives service coordination on a regular basis. Other than service coordination he is receiving no LIDDA specialized services, even though he would benefit from and has been recommended for Independent Living Skills (ILS) and has expressed interest in Day Habilitation (DH). DP had an initial recommendation for Independent Living Skills (ILS) at his Service Planning Team (SPT) meeting of September 9, 2015, but the service did not begin for at least seven months. He enjoyed monthly community trips with the ILS staff person, so much so that the frequency of the trips increased to weekly trips. Unfortunately, the ILS provider was very inconsistent in attendance, missed many sessions, and then abruptly terminated all services. The service coordinator reported that it is very difficult to find staff to work at this location. DP is not currently receiving ILS.

Prior to receiving ILS, DP spent most of his day in bed. He very much enjoyed the occasional community trips and is very disappointed that they have not continued. He told his service coordinator that he is interested in looking at Day Hab and visited one on March 7, 2017, but is not certain he wants to start with a new community provider. His inconsistency around Day Hab should be assessed as the facility social worker and nurse both thought he would benefit from Day Hab services and community activities.

DP Is not receiving any nursing facility specialized services. DP received both PT and OT for a short period after admission to the Villa and his level of functioning improved in both areas. He has also received time-limited, intermittent PT in the past three years in order to increase muscle strength, improve his gait and balance, and increase the distance traveled with his walker. But DP has never received any habilitative therapies or specialized services provided by the nursing facility. He would benefit from an assessment for habilitative PT.

DP is not receiving a program of continuous active treatment of specialized services, consistently implemented. The recommendation for ILS services was not made until September 9, 2015, despite his interest in outdoor activities such as hunting and fishing. It then took at least seven months to implement. Once implemented, it is clear that he greatly enjoyed the community activities. He was deeply disappointed when his ILS provider quit, and the only LIDDA specialized service he received was service coordination. The service coordinator and facility staff state that there are significant problems with transportation to Day Hab, and the nursing facility is not able to transport people both ways. Although a new ILS provider just completed an assessment in the facility, DP has not received any specialized services, other than service coordination, for most of the calendar year. As a consequence, DP spends much of his time in his room, watching television and waiting for his ILS service to occur again on a weekly basis as it did for a short while earlier this year.

DP does not have a professionally appropriate, person-centered individual service plan (ISP) that is based on his strengths, needs, and preferences and includes strategies for addressing barriers to community living. The plan is not based upon a comprehensive functional assessment and he is not receiving a program of specialized services that would prevent regression of his skills. The ISP does not include a list of community services and supports that would benefit DP, nor explain what life in the community would look like for DP. Section 9, Phase II (transition services) is blank. Similarly, information about community living is not individualized or tailored to DP’s interests and needs, although, after consistent urging from a legal advocate, he was finally offered an opportunity to visit a community home.

The service coordinator reports that planning is done in collaboration with the nursing facility staff who, she said, are responsive to requests and will follow through on recommendations. But the plan has one outcome: that DP will receive his chewing tobacco. This is not a goal for him to achieve, but one that is for staff to undertake. There is no mention of any habilitative goals regarding community activities, skill building, transition, or any discussion of barriers and their resolution.

DP would benefit from living in a more integrated setting with supports appropriate to his needs and preferences. He has demonstrated that he is capable of being more active when a service is offered that is tailored to his interests, such as his weekly visits to Cabela’s or his fishing expeditions with a volunteer. The assistance that he requires for his ADL skills is no greater than many people who are currently served in the community and could be provided in a more integrated setting. Due to the lack of specialized services and the segregated setting he lives in, for much of the day his world has shrunk to a semi-private room and watching television.

DP has not made an informed choice to remain in the nursing facility. He has had very little exposure to the wider world beyond Marbridge. He has lived at Marbridge for 60 of his 75 years. Although DP was interested enough to visit one community program and received limited materials about community options, it would be very difficult for a one-time visit of a few hours and a video to be sufficient for him to understand the benefits of living in the community. DP also requested at that visit to tour other community options, but this has not occurred since that request in March 2017. Similarly, DP did not receive options counseling individualized to his interests – something his past experience shows to be important to DP. He should continue to be offered the opportunity to describe what is important to him and determine what types of community activities and transition supports he would prefer. He can see the benefits of the nursing facility – his friends, staff who are kind and caring, and unlimited television – but he does not have an experiential comparison of what his day would be like in a community program and has not been provided that experience. He has spent his entire adult life in a segregated setting but the little time he left to go fishing or to Cabela's were times that he enjoyed and has continued to request without success.

Individual: VC

Fort Worth, Texas Review Date: August 21, 2017

VC is a 75-year-old woman who resides at a nursing facility (NF) in Fort Worth, Texas. She was admitted on March 2, 2016 from a psychiatric hospital. VC was admitted to the psychiatric hospital from another nursing facility on or about February 15, 2016. Her hospital admission record describes her as having severe depression, unable to care for herself, behavior dyscontrol, and mood instability. Prior to being admitted to the first nursing facility, VC lived in a group home in Lewisville, Texas for approximately twenty years and prior to that she lived in an institution in Denton, Texas for approximately twenty years. Her record states that she suffered abuse and neglect when living in the community. VC was unable to remain in the group home because she lost the ability to transfer from her bed without the assistance of a Hoyer lift and the group home could not provide that level of assistance. She is now living closer to her brother-in-law; he says this facility is much better for her.

VC is a legally competent adult, although her recently deceased sister served as her Legally Authorized Representative. Although VC's sister died, VC's brother-in-law has remained active in her life, including her care at her NF. VC is very close with her brother-in-law. He visits VC weekly and talks with her by telephone frequently. She looks forward to both his visit and the food that he brings to her. In one of her psychiatric evaluation, she is described as being motivated by food and that food is used to control her aggressions and behavior.

I met with VC together with her brother-in-law, her service coordinator, and other staff from the LIDDA. VC was seated in a wheelchair. She responded to my questions with short phrases and would frequently look at her brother-in-law. VC had red marks on her legs; staff said she had a wound and will pick at her skin. She has bilateral blindness although she can see images with one eye. She likes music, sitting outside on the patio, and occasionally attends religious services at the facility. She often yells out when she wants something. When I went onto the unit where VC lives, I heard her repeatedly yelling loudly for staff to get her something. VC likes sodas and "honey buns," and is able to gain access to the vending machine to purchase them. VC carries a small pouch around her neck with money for food purchases. She is able to propel her wheelchair, but with her very limited vision, needs assistance.

VC did not have a comprehensive functional assessment of all her habilitative areas that accurately identifies all her individual strengths and needs. She did not have assessments for affective development, auditory functioning, cognitive development, social development, or adaptive behaviors. Despite her psychiatric hospitalization, VC has not had a psychological or psychiatric evaluation since her admission. She had a PASRR evaluation (PE) on April 1, 2016 that was positive for IDD only, despite the psychiatric hospitalization and the characterization that she was depressed and had other psychiatric diagnoses. The PE did not indicate she had any psychiatric diagnosis or a mental illness. She had evaluations for physical therapy (PT), occupational therapy (OT), and speech therapy (ST) within the first month of her admission. She had nursing assessments for her medical conditions and her self-help needs.

VC is not receiving all specialized services that she needs. Despite the recommendations of her PE, VC is not consistently receiving physical therapy (PT), occupational therapy (OT), speech therapy (ST), or alternative placement services. Her initial PE recommends specialized services including service coordination, alternate placement, PT, OT, and ST, and a customized manual wheelchair (CMWC). She received PT and OT from March 15, 2016 until May 12, 2016, but not as a PASRR service. She had a ST evaluation on October 20, 2016 and the therapist suspects silent aspiration. VC has a history of choking when she eats and she has had pneumonia. The therapist recommended a pureed diet with nectar liquids. VC was unhappy with this diet and her brother-in-law requested that she return to a soft mechanical diet because he said that eating was one of the few things that VC had to enjoy in her life. VC's mechanical diet finally was restored six months later, on March 13, 2017. VC is currently receiving habilitative OT, although it is not clear if she has recently stopped attending. She received her CMWC in July 2016 and is very happy with it.

The only LIDDA specialized service that VC is receiving is service coordination, although she would benefit from behavioral supports and has been recommended for Independent Living Skills (ILS) and alternative placement. VC usually screams or yells out when she wants something. Her behaviors are often directed to obtaining food. A behavior support plan, consistently implemented by trained staff, would help VC to reduce the screaming and yelling and substitute more socially appropriate ways to have her needs met. The behavior support could also assist her with maintaining her participation in PT and OT, both of which she needs to prevent regression of her skills.

Although VC's interdisciplinary team has recommended that she receive ILS and she would benefit from the one-on-one attention and increased socialization from this service, at the time of my visit, VC had not yet received any ILS as her service coordinator was still trying to find an ILS provider. VC has almost no opportunities to leave the NF.

VC is not receiving a program of continuous active treatment, consistently implemented. As noted above, she is not receiving any behavioral support, PT, alternative placement, ST, or ILS services and it is not clear if she is receiving OT. She is not acquiring behaviors or skills that would enable her to function with the self-determination and independence of which she is capable. The lack of the ILS services is limiting VC's ability to learn socialization skills and depriving her of participating in other activities.

The facility staff are not specifically trained to work with people with IDD. Staff who provide her daily care should also be trained on implementing the ISP and providing carry-over of the limited services that she does receive.

VC does not have a professionally appropriate Individual Service Plan (ISP). She did not have a comprehensive assessment, as noted above. Her ISP does list her preferences, strengths, needs and concerns. She has four outcomes: 1) to spend time with my brother-in-law weekly; 2) the freedom to choose which activities I participate in; 3) to spend my money at the vending machine; 4) to go to church when I feel like it. All four outcomes are not developmental goals but are statements of her rights as a resident of the facility. These outcomes need to be expressed in the ways in which she would gain skills that would foster self-determination and independence. For example, the spending money outcome could be revised to say that she will learn the value of the different denominations of money, or will recognize and make healthy choices in her purchases.

The ISP is not implemented consistent with her needs: while her behavior of yelling for what she wants is a major detriment to her growth, there is no goal for her to learn positive behaviors to obtain what she desires. Although alternative placement is recommended, the ISP does not identify potential barriers to transition, contains no individualized description of what the community would look like for VC, and Section 9, Phase II was left blank.

VC would benefit from living in an integrated setting with appropriate community services and supports. She was able to live successfully in a group home for twenty years, and the only reason for her admission to the NF was that she now requires a Hoyer lift for transfers. Hoyer lifts are frequently used in community programs and staff can be trained to safely transfer individuals. In addition, receiving PT on a consistent basis could have the benefit of strengthening her legs and upper body to assist in transferring. Reducing her demanding behaviors would enable her to participate in therapies. All these services are available in the community and utilized by others with needs similar to VC.

VC did not make an informed choice to remain in the nursing facility. She has not been provided the specialized services that would enable her to develop skills for living in the community. Her PE of April 1, 2016, shortly after admission to the facility, lists Alternate Placement as one of her specialized services, yet there were only minimal efforts made to seriously explore community living, let alone initiate a transition process. She has been presented the CLO materials on a regular basis but not in a manner that she can understand or appreciate. The lack of ILS, therapies, and behavioral support have left her totally dependent upon the nursing facility for her general welfare. She has regressed in abilities and has a difficult time understanding a different reality than the one in which she currently lives.

Individual: CN

West, Texas Review Date: August 24, 2017

CN is a 53-year-old woman who resides at a nursing facility in West, Texas. She was most recently admitted to this facility on September 11, 2015. Her sister, L, states that she first came to the nursing facility in 1994 or 1995. When the nursing home was destroyed in the ammonia plant explosion in April 2013, CN was transferred to another nursing facility in Hillsboro, Texas during the period of reconstruction. CN previously lived at home with her family until about age 30, when she entered the nursing facility. L said it coincided with the last of the other children moving out on their own. Her parents are now deceased. As far as L knows, the family never received any assistance with CN's care and were never offered any alternatives to avoid institutionalizing their 30-year-old daughter in a nursing facility.

CN is the oldest of seven children. In addition to L, who visits several times a month, her sister, J, works at the nursing home and sees CN daily when she is working. L and J are the most involved with CN; it does not appear that she sees her other siblings.

I met with CN and her sister, L, who is also her legal guardian. CN was seated in a large customized wheelchair and was neatly groomed and appropriately dressed. She smiled frequently at her sister and would turn her head toward the conversation. She was not responsive to my questions. In addition to being non-ambulatory and non-verbal, she has a g-tube. She is very social, enjoys sitting out in the reception area of the facility and attending various activities, such as bingo, polka boys, birthday parties, and other music based events. She will vocalize when she wants to leave her room and go to activities and is out of her room every day. She does not leave the nursing facility as her wheelchair is too large for the facility van.

CN has cerebral palsy, GERD, scoliosis, and recurrent urinary tract infections (UTI). She had four emergency room (ER) visits in 2016 for UTI or complications from her g-tube. She was admitted to the hospital in January 2017 for a UTI for four days and had an ER visit in January for g-tube complications. Her sister and the nursing staff described several recent episodes of "staring off into space" and seeming to be absent. She has had a CT scan and it was negative. She is scheduled to see a neurologist in November 2017 to follow up. She also had an incident in July 2017 where she was discovered by the nursing staff with numerous "fire" ants crawling up her body as far as her shoulder. She had over 100 bites on her body. The facility investigated and could not determine how the ants were able to access her room and cover so much of her body before the problem was discovered.

CN did not have a comprehensive functional assessment of all her habilitative areas that accurately identifies all her individual strengths and needs. Despite the fact that she has a neuromuscular disorder, cerebral palsy, she has not had evaluations for occupational therapy (OT), physical therapy (PT), or speech therapy (ST). She also has not had assessments of her sensorimotor development, nutritional status, affective development, speech and language development, auditory functioning, cognitive development, adaptive behaviors, and vocational skills. She had a PASRR Level 1 done on March 26, 2013 – almost twenty years after she was admitted to the nursing facility — that is positive for IDD. She had PASRR Evaluations (PE) done in January 2014, March 2015, and in November of 2015. They are inconsistent, with some finding that CN has a mental illness, and others that she has developmental disabilities, or intellectual disabilities, or both. She does have a developmental disability – cerebral palsy – but there is no record of her intellectual level of functioning and she does not have a diagnosis of a mental illness or displays symptoms of one. Most of the PEs generally state that she expects to remain in the nursing facility and the only specialized service recommended is service coordination. However, the November 24, 2015 PE states that she is appropriate for a group home, that she could be served in the community, and that the family would not support leaving the facility. It appears that no action has been taken to implement this recommendation and no effort to seriously explore community transition.

Over the course of the past decade, CN has had thirteen MDS assessments by the nursing staff of the facility. She had an OT evaluation on October 21, 2016 for a special air mattress due to a stage II decubitus ulcer on her buttock. These assessments take place over a wide range of time and are not done in collaboration as part of a team response to evaluating her needs, strengths and preferences

CN is not receiving all necessary nursing facility and LIDDA specialized services. CN has not received any of the NF specialized services that she needs including PT, OT, or ST, despite the diagnosis of a neuromuscular disorder, cerebral palsy. She does receive restorative nursing program of passive range of motion of her extremities four times a day, but she would benefit from an evaluation by a licensed PT and OT to assess her current status. The only nursing facility specialized services CN has received are the special air mattress, based upon an OT evaluation on October 21, 2016 recommending the mattress, and possibly a customized manual wheelchair.

CN is receiving only one of the LIDDA specialized services that she requires – service coordination. After not receiving any other LIDDA specialized services for almost twenty years, on February 8, 2017 her SPT recommended Independent Living Skills (ILS). However, at the time of my visit in August, CN still had not been evaluated by the agency that provides ILS because, as explained by her service coordinator, there are only two ILS providers that serve the nursing facility and neither of them has any openings. The service coordinator stated that it is difficult to find staff to work in the program and the agency relies upon interns who turn over frequently. In addition, he stated, people who are able to leave the facility are given priority for ILS, and so he believes that CN will always remain at the bottom of the waiting list for ILS. All nursing facility staff and her sister agreed that CN would benefit from the one on one attention from ILS.

In addition, CN should be assessed for Day Habilitation (DH), as she is the same age as many people in DH and it would provide her with the socialization and outside activities she desires. However, the service coordinator stated that there are only two DH providers who could meet her needs, including the g-tube; that it is very hard to find an opening, and the problem of obtaining transportation for CN to go to DH would be “huge.”

CN is not receiving a program of continuous active treatment, consistently implemented. As described above, she is not receiving virtually any of the necessary specialized services that would assist her in gaining or retaining skills to promote her independence and self-determination. She has not received the recommended service of ILS for over six months. She is not receiving therapies that would maintain or increase her functional ADL skills. It is not known what her intellectual level of functioning is, even though the assumption is made that she is delayed. However, a diagnosis of cerebral palsy does not necessarily mean that a person is also intellectually disabled. She should be evaluated to see if there are switches or electronic devices she could operate that would increase her independence. The staff of the facility are not specifically trained to work with people with DD and there is no carry-over of her activities. Finally, due to a lack of transportation, she is never able to leave the nursing facility and so has very limited socialization opportunities. She is much younger than the average nursing home resident and has been there since age 30.

CN does not have a professionally appropriate Individual Service Plan (ISP). It is not based upon a comprehensive assessment as described above. The service coordinator does include the nursing facility staff and her family in all SPT meetings, and there is good communication between the service coordinator, the nursing facility, and the family. The ISP identifies some of her strengths, needs and preferences, and provides information regarding her medical, clinical, and other need areas. But her ISP has only three outcomes, none of which have anything to do with gaining functional skills or increasing independence: 1) to have regular visits with my family; 2) to wear jewelry daily; and 3) to socialize in the facility. Her goals have remained the same for the last three years. Her ISP is not a person-centered plan because her goals do not recognize her preference for socialization and explore whether or not she could attend a day habilitation program or access the community with appropriate transportation. Her wheelchair is no different than many that can be accommodated in a wheelchair van. Section 9, Phase II of her ISP is blank, and there is no concrete description of what living in the community would look like for CN.

CN would benefit from living in an appropriate community setting, with 24-hour staff support and necessary services. Her needs are not any different from many people who successfully live in the community and attend day habilitation programs, go on outings, and are engaged members of their communities. The service coordinator and the nursing facility staff agree that she could live in the community with the proper supports for her medical issues and self-care needs. In addition, the PE of November 24, 2015 recommends a HCS placement in the community. She is much younger than most of the other residents of the facility and she has successfully lived in the community prior to coming to the facility at age 30. She was cared for by her family without assistance.

Although CN's family previously was open to considering a community placement CN's guardian now insists that she should remain in the nursing facility. The service coordinator has presented the Community Living Options (CLO) at the prescribed intervals, provided individualized information regarding community programs, and repeatedly offered opportunities to visit community living options. He identified the barriers to placement and indicated that he continues to provide information to the guardian. In my meeting with the guardian, she stated that she felt that CN was best served in the facility because the staff know her, the facility has the medical expertise to care for her, and it is convenient for the family to be involved with her there. She stated she is aware of the options and that the service coordinator has provided her with sufficient information in an appropriate manner that she can understand.

Individual: DK

Fort Worth Texas Review Date: August 22, 2017

DK is a sixty-five-year-old woman who resides at a nursing facility in Fort Worth, Texas. She was admitted on August 11, 2015, as a result of a fractured hip that occurred while visiting her brother J's apartment. The initial MDS assessment of August 11, 2015 states that she came from the community, not a hospital. The service coordinator did not have information regarding her admission, and has only been her coordinator for about six months. The nursing facility record and PASRR Evaluation (PE) state that she previously lived in a group home in the community and attended a day habilitation program. DK confirmed that she lived in a group home and that her brother, C, although not legally authorized, placed her in the nursing facility, but this was not verified by the nursing facility staff or the review of the records. She has two brothers, J and C, and a sister who lives in New Hampshire. She stated that she wished she could see her sister. Her brother C comes to visit her and is involved in her care plan meetings. The nursing facility staff stated that they have restricted visits from her brother J at DK's request, due to his moving things around in her room which caused her to fall and his overly solicitous manner with her.

DK is ambulatory, although she will sometimes use a walker or cane for assistance so it appears that she has had sufficient healing from the hip fracture to be mobile with minimal assistance. She was responsive to talking with me and was articulate in providing information. Her room was neat and clean and she had a number of personal items. She was very fond of a doll and poignantly said that her doll doesn't have any seizures. She says she likes to be active and enjoys going to the therapy room. She also likes bingo, arts and crafts, coloring, and going on outings to the store and the movies. She described the event that precipitated her admission to the NF as falling at her brother J's apartment and hurting her hip. She showed me a bruise on her ankle which appeared to be the vascular condition of angiomas. In addition to her previously fractured hip, she has a seizure disorder and wears a helmet for protection. She has had a number of falls, five during a seven and half month period since the end of January 2017. Two of the falls in February were related to a seizure and caused minor injuries.

Initially, in November 2015 during a meeting with the Local Authority (LIDDA), DK's brother J stated that he did not want DK to receive any PASRR services including service coordination and did not want her to return to the group home. The nursing facility staff asked the service coordinator to speak with her other brother, C, and at a subsequent meeting C agreed to PASRR services which DK accepted. Significantly, DK is legally competent to make her own decisions.

DK did not have a comprehensive functional assessment of all her habilitative areas that accurately identifies all her individual strengths and needs. She did not receive assessments regarding her cognitive development, independent living skills, and vocational skills. She had a PASRR Level 1 done on August 10 and 25, 2015 which is positive for ID. She had an initial PE on September 10, 2015 and again later in September 2015 and then again in February 2016, all of which recommended various specialized services. She has had multiple MDS evaluations, with the initial MDS done on August 11, 2015. For unexplained reasons, the nursing facility's assessment states that she does not qualify under the PASRR system as a person with either an IDD or mental illness (MI) disability. That erroneous assessment was corrected in a later August 18, 2015 MDS report. In September 2015, she received evaluations for physical therapy (PT), occupational therapy (OT), and speech therapy (ST). She has received nursing assessments regarding medical/nursing concerns such as fall risk and skin integrity. The assessments that she did receive were not done contemporaneously or collaboratively and as part of an interdisciplinary team with the goal of producing an integrated picture of DK's strengths, needs and preferences.

DK is not receiving all necessary specialized services. Although recommended in her PE, DK has not received consistently received habilitative PT, OT, and ST. The PE of September 10, 2015 recommends PASRR services of PT, OT, and ST; the PE of February 22, 2016 also recommends PASRR of PT, OT, and ST. She has received PT intermittently during the past two years, first from September, 2015 through October 2015, then in January through June 2016, then again in August through November 2016, and possibly into February 2017. She also received OT at those same times with slight variations in the same start date. She received ST from the end of August to September 2015, in January to February 2016, September to November 2016, and January to February 2017. The documents reviewed are not clear if any of these therapies were provided under PASRR, although it appears from service coordinator notes that most in 2016 and 2017 were at least recommended as PASRR services. There is no documentation in nursing facility records how the services were actually provided for the other dates listed in the MDS.

The therapy staff stated that she is currently getting OT and PT five times a week, but it is unclear if these are PASRR services. The staff have repeatedly asked for help from the service coordinator but he said that he is unable to provide the requested assistance because he was told by his supervisors that service coordinators are not permitted to assist the NFs with the PASRR process. As a result, it is not clear whether these services actually are provided through PASRR. It does appear that DK has received rehabilitative rather than habilitative (PASRR) therapies for several months. Given DK's history of fractures and her frequent falls, it is very important that DK receive PT and OT on a consistent and ongoing basis, and that these therapies are provided continuously and consistently, as habilitative services, and not intermittently, as rehabilitative services. Her ability to ambulate is already compromised, and it is important that she have as much functional ability to independently ambulate as possible.

DK is not receiving any LIDDA specialized services except service coordination. She would benefit from Independent Living Services (ILS) as she likes to be active, participates in many of the activities at the nursing facility, and likes going on outings. Without it she has little, if any, opportunity for community activities or experiences. The one-on-one companionship from a person skilled in working with people with IDD will help her to maintain her level of skills in the areas of self-care, socialization and community access. Prior to admission she was in a Day Habilitation (DH) program and should be assessed for interest in a DH that would be appropriate to her interests, skills, and needs.

DK is not receiving a continuous program of active treatment, consistently implemented. She did not receive a comprehensive functional assessment conducted as part of single, collaborative effort that formed the basis for determining the specialized services that would help her to retain and improve her skills for independence and self-determination. Her therapies are not delivered continuously as she has had periods without any therapy as occurred during January through April of 2016. She has a history of a fractured hip, osteoporosis, and frequent falls since admission to the nursing facility and requires the services of skilled therapies to minimize loss of functional ability resulting from loss of muscle strength, balance, and coordination. The staff at the facility have not received specialized training in working with individuals with IDD.

DK does not have a professionally appropriate Individual Service Plan (ISP). Her most recent ISP is dated April 13, 2017. The plan is current with information regarding her strengths, needs, and preferences. It reviews her medical/nursing needs and provides information on her therapies. But she has only three outcomes: 1) to be out of her room on a daily basis, 2) to participate in activities, and 3) to be able to color in the coloring books. These outcomes are not sufficiently geared to assisting her to increase her skills, and to increase her abilities to function as independently as possible. They are not functionally-oriented; being out of a semi-private room on a daily basis should be standard practice and not an achievement to be working toward. Her ISP is a not a person-centered plan because the goals do not describe specific ways in which she could grow through participation in activities such as attending one community outing of her choice weekly with her ILS staff person. While she clearly enjoys coloring in coloring books, a habilitative goal should be something like taking an art class of her choosing at a local art school or attending the public library coloring book monthly event with the assistance of her ILS staff person. The ISP does not at all address transition issues or have goals which would assist her in making an informed choice about community involvement such as visits to DH programs or the implementation of the ILS service. The ISP does not identify potential barriers to the community or contain an individualized description of what the community would look like for DK. Section 9, Phase II is left blank.

DK would benefit from living in an integrated setting with appropriate community services and supports. All of the nursing staff interviewed, including the therapy department staff, believe she could live in the community with supports. The service coordinator stated that she could be served in the community and that there are about 260 HCS providers in Tarrant County. She lived in the community in a group home just prior to her admission to the nursing facility. She does not have any medical conditions that could not be supported in the community. She is ambulatory, and has minimal needs for assistance with self-care. She would need a program with 24-hour staffing. It appears the major barrier to living in the community is that her brothers do not support her return to the community.

DK has not made an informed choice to remain in the nursing facility. Despite the nursing facility staff belief that DK could successfully live in the community, Section 9 phase 2 of her ISP has not been filled out and no exploration of community options based on DK's strengths, preferences, and interests has occurred. She has exhibited reliance on her brothers in the past, even when she did not agree with them, as evident from her change to accepting PASRR services that J declined. The ISP and the CLO consistently state that she wants to remain in the nursing facility and list barriers of liking the nursing facility staff and having friends in the facility. Obstacles to removing those barriers are that she would be able to like her new staff and make new friends. There is no indication that these and other barriers to community – including her brothers' concerns about the community – have been addressed. The SC has not offered specific plans to address DK's concerns and fears about transitioning back to the community. DK has not been offered the opportunity to visit community living options nor has she received ILS services to introduce her to community living again or increase her number of outings into the community. Most tellingly, when I spoke with her about living in the community again she stated to me "I am supposed to like it here." She then repeated it a second time, "I am supposed to like it here."

Individual: JM

Bartlett, Texas Review Date: August 16, 2017

JM is a 57-year-old gentleman who has resided at a nursing facility in Bartlett, Texas since 2009. He has a severe intellectual disability and cerebral palsy. When I arrived at the nursing facility, he was sitting outside in a wheelchair, in the fenced in courtyard area. After interacting with me for a few minutes, he propelled himself back into the nursing home, navigating the sidewalk and automatic door easily. One of his ears was swollen and red, and he kept pulling at it as though it was bothering him.

JM was apparently first admitted to a nursing facility on April 27, 2005 after breaking an ankle when he fell off the porch of his brother's house, where he lived. Until 2005, JM lived for many years with his brother or parents following a long stay in an ICF/IID when he was a child and teenager. He spent almost a year in another nursing facility, Temple Living Centers- Western Hills, after suffering a fractured neck of his femur in 2008. Since then, his health has been stable. He requires assistance with ADLs but can transfer with a one-person assist. He can get out of his wheelchair independently, and move to the floor to play with trucks and cars, but he needs assistance to get back into the chair.

The nursing staff says that JM maneuvers around the facility including outside with ease. He rarely spends time in his room, preferring to look out windows or be outside in the courtyard. He has several friends and plays with his toy guns. He will contact the staff if he feels another resident needs help. He can independently use the CD player and television. He follows the activities calendar and independently accesses activities. He likes to go on community outings and to the nearby public library. The service coordinator stated that he goes out of the facility about three times a month. He is legally competent to make decisions and has a brother and sister-in-law who live in a neighboring town.

JM has not received a comprehensive functional assessment of all his habilitative needs, including his strengths and preferences while in this nursing facility. He does not have assessments of sensorimotor development, affective development, auditory functioning, cognitive development, or social development. Despite a diagnosis of dysphagia, which typically necessitates a speech therapy assessment, JM has not received a speech therapy assessment. From the nursing facility records, it appears his first PASRR Level 1 screening was on March 18, 2013, which was positive for both intellectual disability and developmental disability, due to his cerebral palsy. A PASRR Evaluation was not done until almost a year later, on March 20, 2014. The evaluation confirmed that JM has an IDD, but did not recommend any specialized services except for service coordination and a CMWC. It states that he prefers to remain in the nursing facility. He has had multiple MDS nursing facility assessments, including evaluations regarding fall risk, mental status, ADL skills, and similar nursing concerns. He had a physical therapy (PT) evaluation in 2016. His assessments were not done in collaboration with each other but instead at varying points in time, and do not present a cohesive and comprehensive description of his needs and strengths.

JM is not receiving all necessary specialized services, even though he could benefit from and needs these services to maximize functioning and avoid deterioration. JM is only receiving two specialized services: a customized manual wheelchair and service coordination. He had PT for six weeks in 2016 to help with right knee extension and to work with seating on his wheelchair. He had a wound on his ankle from dragging his foot along the floor, because the wheelchair was too low. He was discharged from PT in June 2016 after some improvement and a finding that his goals were met, but without regard to the benefit of ongoing, habilitative PT. JM would benefit from a PT assessment to determine if gains could be made in his transferring abilities and his range of motion in his legs, and if JM would benefit from ongoing PT to maintain his current functioning. Since he improved during his brief, rehabilitative PT in 2016, JM most likely would continue to gain skills and at least maintain his current functioning. He does receive restorative nursing services six days a week for his upper extremities and grooming, but has not had an OT assessment. He would also benefit from a speech assessment to determine his aspiration risk because of his dysphagia diagnosis.

JM is receiving no LIDDA specialized services other than service coordination. JM needs, and would be appropriate for, Independent Living Skills (ILS) because he likes going outside, be busy, and would benefit from skill development and maintenance of existing skills. The one-on-one attention would enable him to explore more interests, since he is described by everyone as always out of his room and very social. He also should be assessed for Day Habilitation (DH), given his social nature and need for ongoing skill development. However, the service coordinator stated that it would be difficult to find ILS and Day Hab providers that would serve and transport a person in a wheelchair – so this service has not been recommended, despite the potential benefit it would afford JM. Significantly, the nursing facility staff all agree that he would benefit from PT, OT, ILS and the opportunity to explore DH, but he is not receiving any of these four services.

JM is not receiving active treatment. He is not receiving the necessary specialized services that would enable him to function with as much self-determination and independence as possible. He is not provided therapies such as PT that would enable him to acquire and/or maintain skills in mobility and transferring. He has minimal interaction with the community, going out only about three times a month, despite being very social. Nearly all of his time is spent within the confines of the nursing facility. The nursing facility staff are not trained to provide services specific to individuals with IDD.

JM does not have an appropriate, person-centered Individual Service Plan (ISP) that is based on his strengths, needs, and preferences and includes strategies for addressing barriers to community living. There is only one statement listed on JM's ISP as a strength, and half of his preferences focus entirely on eating. JM's ISP has only two outcomes: 1) to attend social activities and 2) to sit outside or look out the window. These are very limited outcomes and poorly reflect JM's social nature and potential – something that could be supported with ILS and access to community activities. The ISP does not contain a detailed description of community alternatives or a discussion of barriers to community placement. Section 9, Phase II of the ISP (transition services) is left blank. Instead, the ISP simply states that JM prefers to remain in the nursing facility, despite his years living in the community and his desire to remain active and social. It does not see JM beyond his fascination with his toy guns and outlines a life of minimal opportunities for growth and self-determination.

JM would benefit from living in the community in a program that has appropriate supports and services. While the admission to the nursing facility is described as the result of a lack of adequate supports during his prior community experience, there is no evidence of any effort to address this concern or identify a more appropriate provider, particularly since JM's care needs are not different from other individuals who live successfully in the community. The assistance he requires with his ADL needs are no different from those provided by community agencies and his opportunities to participate in social activities would be enhanced living in the community.

JM has not made an informed choice to remain in the nursing facility. While he has been presented with some general information on community services, the limited information provided is not tailored to his cognitive abilities, does not provide choices that he can understand, and, most importantly, is not designed to engage him in a conversation about community living. JM rarely leaves the nursing facility, has not toured any community programs, and does not interact with persons other than staff or other nursing facility residents. He has no experiential knowledge of community services since his admission to a nursing facility in 2005. Neither his ISP nor the Community Living Options (CLO) documentation describe what the community would be like for JM, including where he might live, who he might live with, what he might do, and how his needs and preferences could be met. Given his cognitive impairments and the lack of exposure to the community, it is very hard, if not impossible for him to understand that he actually has a choice, let alone weigh the risks and benefits of that choice. Moreover, no meaningful, concrete choice has been offered to JM since he has not been provided any individualized information about more integrated options that could reasonably support his needs.

Individual: SB

White Settlement, Texas Review Date: August 22, 2017

SB is a 25-year-old woman who was admitted to a nursing facility in White Settlement, Texas on September 16, 2016. An articulate young woman who ambulates with a wheelchair, SB easily answered my questions and responded fully. She is legally competent to make her own decisions. She had a thorough understanding of her major health challenge, lupus, and described the impact of the disease on her life. She has a colostomy and a urostomy. She has several stage 4 wounds; located on her right ankle, right ischium, right hip, and left ischium. Diagnosed with transverse myelitis, she is a paraplegic and uses a wheelchair. She does not have feeling below her mid-chest. Just prior to her nursing facility admission, SB was living with her mother until she was hospitalized after she found blood in her urine. Immediately following her discharge from the hospital, SB was admitted to the nursing facility on September 16, 2016. She had four wounds that required extensive treatment with a wound vacuum to promote healing. She also had difficulty with her urostomy and supra-pubic catheter leaking. In the past, before living with her mother, SB lived independently in an apartment in San Antonio.

Since her admission to the nursing facility, SB has been hospitalized three times: from January 19, 2017 until January 25, 2017 for a deep vein thrombosis; from February 13 to February 17, 2017 for cellulitis; and from March 24 until April 10, 2017 for a flare up of her lupus. She has chronic pain syndrome and receives prn pain medication, usually twice daily. Despite these medical challenges, she is positive and very much wants to leave the nursing facility. She received her GED at age 18 and has attended college. She talked about wanting to go back to college and thinks she would like to work in IT. She is thinking about taking an on-line college course now, but would need a laptop to participate. Her mother participated in the interview after SB called her on her cellphone. SB also talked about her grandmother, who is close to her. SB described her hopes and dreams for the future, that she does not have a peer group at the NF, and would like to live in a host home. SB was very clear that she would like to leave the nursing facility and live in the community. She recognizes that she would need significant supports and would prefer a host home, but would also consider a group home. Both her mother and grandmother are supportive of her return to the community.

SB did not receive a comprehensive functional assessment of all her habilitative areas that accurately identified all of her strengths and needs. SB did not receive assessments in the areas of affective development, speech and language development, adaptive behaviors, and independent living skills. She had a PASRR Evaluation (PE) on September 20, 2016 which recommends the nursing facility specialized services of occupational therapy (OT), physical therapy (PT), and a customized manual wheel chair (CMWC). Local Authority (LIDDA) specialized services recommended are service coordination (SC), alternate placement, Independent Living Skills (ILS), employment assistance, supported employment, and day habilitation (DH). She also received OT and PT assessments in September 2016 which identified her needs for those services. Through the MDS process, she received an assessment of her self-help skills and needs. The assessments that were done were not conducted in collaboration with various professionals and present a fragmented picture of her strengths, needs and preferences.

SB is not receiving all of the specialized services that she needs. Although the PE of September 20, 2016 recommended nursing facility specialized services including OT and PT she has not consistently received either. Additionally, it was recommended that SB receive a CMWC and DME, including an air mattress. She has received her CMWC through PASRR and she has an air mattress that was not obtained through

PASRR. Through PASRR, she received OT and PT from September through December 2016 and again in January and February 2017 for a brief time. She was again provided OT and PT in April and May 2017, but this is scheduled to terminate in September 2017. There are major gaps in PT from the end of January until May 2, 2017 and in OT from the end of January until April 12, 2017. While SB could not receive these therapies while hospitalized, she would have benefitted from a much prompter resumption of these therapies once she returned to the nursing facility.

The nursing facility reports that the PASRR system is challenging to use, that the form is time consuming to fill out, and there was some confusion around how long they could request therapies. Initially, they believed that it was monthly, as is true for Medicare.

SB has been offered ILS, BH, and Day Hab and would like to participate but her health has declined due to her wounds. She is interested in exploring Day Hab and ILS as soon as possible. She has been offered a list of providers to tour for an alternate placement and is interested in pursuing community placement.

SB is not receiving a program of active treatment, consistently implemented across all settings. The interruption in OT and PT, following her hospitalizations, has meant that she has not progressed as rapidly as she could have in learning and/or maintaining skills in transferring, dynamic balance, functional activities, upper extremities range of motion, and dressing herself. Staff who work with SB on a regular basis, such as nursing assistants are not trained to carry over the skills that are being worked on in OT and PT. The nursing facility staff has not been trained to work with a person with a developmental disability. SB is not receiving active treatment that will help her to maintain the skills she mastered when she lived with her family or in the apartment. She has consistently stated from the time of her admission and throughout all of her team meetings and to date that her goal is to return to the community. She needs to have continuous support to maintain her many skills and to increase her independence, in order to achieve this goal.

SB does not have an Individual Service Plan (ISP) that is appropriate to her developmental strengths, preferences, and age. The three outcomes in her ISP are to 1) maintain contact with her family; 2) play keno and video games; and 3) find a dentist who will take my insurance. These goals do not recognize her desire to return to the community and the need to maintain her functional ADL skills for maximum independence. These goals also fail to recognize her oft-stated desire to return to college and take an on-line course. Since she is a young person who has attended college, this is not an unrealistic goal and one that she could have as part of her current ISP. The ISP is not a person-centered plan because the goals are focused primarily on activities and skills within the nursing facility and not in the community as she desires. The goal of finding a dentist has been assigned to her mother, and because of her work schedule, has not been met. The family or SB should not have to implement this important goal; it should have happened within three months of being written which was nearly a year ago. The ISP does incorporate transition planning for her return to the community and a discussion of her options and barriers at each team meeting. Although the service coordinator stated that there are providers capable and willing to provide the level of health care that SB will need in the community, her ISP does not identify necessary supports, contains no individualized description of what the community would look like for SB, and Section 9 Phase II was left blank. No action has been taken to initiate the transition process.

SB would benefit from living in an integrated setting in the community, with appropriate supports. As a young person, who only very recently had to enter a nursing facility, the community is her natural environment. SB wants to return to the community and her family is supportive of that goal. She will need medical supports to manage her wounds, either through the provider or a home health care agency. She will need accessible housing due to her wheelchair and transfer needs. SB will also need twenty-four-hour staffing and assistance with ADLs, medications, and coordination of health care, including doctors' appointments. These barriers have been identified by the team and a planning meeting to discuss these issues was scheduled to occur the day after my visit, August 23, 2017.

SB has made an informed choice to leave the nursing facility and to return to the community. She does not have an intellectual disability and has experienced community living for nearly all of her life with the exception of the past year. She has consistently stated that goal from the beginning of her admission in September 2016 through to the date of my visit. She recently has been offered the options of either a group home or a host home and is considering both. She has had CLO meetings as required and the barriers to her placement have been discussed. She understands that her wounds present a barrier, but they are healing now and it is possible for her to receive community-based wound treatment from a home health agency, just as many other people do.

Individual: TS

Bartlett, Texas Date of Review: August 16, 2017

TS is a 56-year-old gentleman who resides at a nursing facility in Bartlett, Texas. He was admitted to the facility on April 28, 2012. Prior to his admission to the nursing facility, TS attended a school for the blind in Dallas. He was a cabinetmaker and worked in an ice cream parlor. He resided in a community setting with IDD services for over 20 years. It is not clear from the record if he came to the nursing facility directly from his community provider or from an acute care hospital. The record does indicate that he experienced declining health and abilities. In addition, his father does not think that he received adequate care at the community provider. TS's health has declined further since his admission to the nursing facility in 2012. Previously he was responsive to others and enjoyed activities and visits from his father. He suffered intestinal abscesses in October/November 2014, and was no longer able to eat by mouth. As recently as November 2016, he was able to attend nursing facility activities several times a week. In January of 2017, he was placed on palliative care. In February 2017, his father requested that his seizure medication, Keppra, and all laboratory studies be stopped. Subsequent to stopping the medication, he had seizures and was placed back on Keppra in June 2017, and now is receiving laboratory studies as necessary.

TS was resting in bed when I visited. He did not respond to my greetings, and the nursing facility staff state that he is unresponsive to all communication. He did hiccup a few times and had facial grimacing, possibly due to the fact that he had just received his g-tube feeding. He appeared comfortable, was clean, and was lying on his side. He had a contracture of his right wrist. He likes country music, which was playing softly on the radio in his room. Staff report that they get him up and out of his room every day. He uses a Geri-chair because of a lack of trunk control. He has diagnoses of a profound intellectual disability, past history of brain tumors at age 11, a traumatic brain injury from an automobile accident, encephalomalacia, pan hypopituitarism, seizures, dysphagia, blindness, and a history of peritoneal abscess, acute and subacute bacterial endocarditis, and MRSA. His father is his legal guardian.

TS did not receive a comprehensive functional of all his habilitative areas that accurately identifies his individual strengths and needs. He did not have assessments in the areas of sensorimotor development, affective development, social development and adaptive behaviors. Despite his diagnosis of dysphagia and his feeding tube, he has not received a speech therapy (ST) assessment. He received MDS assessments from the nursing facility as required, and physical therapy (PT) and occupational therapy (OT) assessments at various times, but not in a coordinated manner. He received a PASRR Evaluation on March 20, 2014, nearly two years after his admission in 2012.

For the past five years TS did not receive the specialized services needed to maximize functioning and avoid deterioration. Finally, one week before the fact cut-off date, TS began receiving PASRR PT and OT, but each of these services were only approved for 30 days, despite his need for continuous and ongoing therapy. At the PASRR Evaluation of March 23, 2014, the only specialized services recommended were service coordination and a customized manual wheelchair (CMWC). He is receiving service coordination as required and he has a CMWC, but he is no longer able to use it. He uses a Geri-chair instead. He should have been evaluated at that time for OT and PT, because he was already showing a decline in his functional abilities. A decline in these abilities is listed as one of the reasons he had to leave the community provider. He also had a diagnosis of dysphagia, had a feeding tube, and should have received a speech therapy assessment (ST). At that point in his life, he would have benefitted from Independent Living Skills (ILS) as he would have enjoyed the companionship of a person specifically chosen to spend time with him and benefited from the maintenance and acquisition of skills that ILS is intended to facilitate. These years of higher functioning are now gone, and the services he could have benefitted from, but never received, cannot be altered.

When I met TS on August 16, 2017, he was not receiving any habilitative therapy services, despite his need for PT and OT and the nursing facility staff's acknowledgement that he would benefit from these services to prevent further contractures. Since that time, TS began receiving PASRR PT and OT on August 18th and 25th, respectively. TS previously received PASRR PT and OT in the last half of 2015 until January 2016 and time-limited rehabilitative OT and PT from roughly November 2016 to January 2017. TS would have benefited from a continuation of habilitative PT and OT that he did not receive from January 2016 to August 2017.

Currently, TS has a professionally appropriate individual service plan (ISP). TS is on palliative care and appears non-responsive to external stimuli. His two outcomes recognize this and provide for continued social interaction. The outcomes are to: 1) have his father visit; and 2) listen to country music and be among others. The nursing facility staff state that they get him out of his room every day; he continues to attend some activities, although he does not participate. His guardian, who is also his father, has declined community placement.

Given his current health status, TS would not benefit from community placement. He is on palliative care. He is apparently non-responsive and has been in a gradual decline in his level of responsiveness for the past two years. Due to his non-responsive state and his continuing decline in health, TS would not be able to enjoy the benefits of community living and the transition to a new setting, with unfamiliar staff could negatively impact TS's condition. People with TS's level of functioning and health status are successfully served in the community and hospice can be provided to them as they journey to the end of life. However, given his stay at the nursing facility since 2012 and his continuing decline, as evidenced by being on palliative care, it would be disruptive to TS to leave the nursing facility.

His guardian has made an informed choice to have TS remain in the nursing facility. TS's non-responsive state renders him incapable of understanding or making any indication of his preference to live in the community. TS's guardian has been provided information about community options in a format that he can understand. TS's guardian – taking into account TS's condition, continued declined in health, and past experience – has indicated a disinterest in community placement.

Individual: AS

Waxahachie, Texas Review Date: August 25, 2017

AS is a fifty-six-year-old gentleman who resides at a nursing facility in Waxahachie, Texas. He was admitted on April 17, 2013. AS has a twin, who is not disabled, brothers, and sisters. The record indicates he has five siblings. AS is legally competent to make his own decisions.

AS lived at home with his family for many years. His mother cared for him until she no longer was able, at which point, he moved in with his twin brother. His sister, B, stated that there were problems with his care, he became ill, and was hospitalized. After the hospitalization, AS moved in with his sister M, but she found that his care was too demanding and placed him in a nursing facility closer to her in Dallas. They decided to move him to this nursing facility to be closer to B and his two brothers. M would like him to move in with her with supports. It appears that AS did not make an informed choice to leave the community and move to this facility.

I first met with his sister, B, who was very prepared for my visit. B stated that their sister, M, has medical power of attorney and is the one in the family who makes decisions regarding AS. B comes to the nursing facility frequently and attends all of his medical appointments because M works and lives in Dallas. One of the brothers comes every day, visits him, and picks up his laundry which B cleans for AS. B stated that the family is not pleased with this facility, and have had complaints about the frequency of bathing, that his feet are not properly cared for, and his skin care needs are not being met. The family also had concerns about his wheelchair. They stated that he had his own customized wheelchair but they don't know what happened to it, so now he has to use one that belongs to the nursing facility. They filed a formal complaint regarding some of his clothes which are missing. His siblings often take him to family events and to church.

We met with AS in his room, where he was in a wheelchair, visiting with a friend. He answered my questions, but was clearly involved in a conversation with his friend, so I left him to socialize. The staff of the facility told me that he likes to sit at the dining room table with his friends and likes music, shopping, and Bible study. AS is a diabetic who requires insulin and gets finger sticks four times a day. He is often not compliant with his diet and had an ER visit on April 7, 2017 for high blood glucose level and a more recent ER visit due to a fall. The NF staff said that he will sometimes gorge on food and then will vomit in bed. If that happens, they take his clothing and launder it in the nursing facility; they believe that is what happened with the missing clothes. In addition to diabetes, AS has glaucoma for which he sees an eye specialist every two to three months. He also sees an endocrinologist in Dallas. His sisters, B and M accompany AS on his endocrinologist visits.

AS did not have a comprehensive functional assessment of all his habilitative areas that identified his strengths and needs. He did not have assessments in the areas of sensorimotor development, affective development, auditory functioning, cognitive development, social development, vocational skills, or independent living skills. There was no nutritional evaluation in the records I reviewed. He had a PASRR Level 1 on May 3, 2013, which confirms mental illness and developmental disability (DD), but not an intellectual disability (ID), even though he has no psychiatric diagnosis nor does he display symptoms of a mental illness. He had a PASRR Evaluation (PE) six months later, on February 15, 2014, which is positive for DD and not for ID or mental illness. There are no earlier PEs in the records I reviewed. He has had multiple MDS assessments in 2015, 2016, and 2017. He had a psychological assessment in June,

2015. He had a physical therapy (PT) evaluation in April 2015, an occupational therapy (OT) evaluation in September 2015, and a speech therapy (ST) evaluation in October 2015. These assessments were not done in collaboration and within the same point in time, usually a thirty-day time period, but instead over a two year period.

AS is not receiving all needed nursing facility or LIDDA specialized services. The PE did not recommend any specialized services other than service coordination. As a result, the only specialized service that AS is receiving is service coordination. Though AS would benefit from the NF specialized services of habilitative PT, ST, and OT to maintain and improve skills, he has not been recommended for or received these services. At all of his quarterly service planning team (SPT) meetings, AS indicated that he does not want or need any PASRR services, although he is receiving service coordination and has participated in various rehabilitative therapies.

AS has a diagnosis of athetoid cerebral palsy and would benefit from PT for muscle strength, balance, mobility, and transfers. He would also benefit from OT for upper body muscle strength, relief from the contracture of his arm, transfers, ADL skill retention, and acquisition of safety awareness. He would also benefit from ST; he had a dysphagia evaluation on May 6, 2013 and again on May 16, 2017. The 2017 evaluation states that he is at HIGH risk for aspiration. AS has had intermittent therapies for rehabilitation, but these services have not met all of his needs, are not ongoing, and are not available to maintain skills and functioning. For instance, he had OT in August-September 2015, in April and May in 2016, and again in November and December of 2016. He had PT in April-June in 2015, and then in January and February in 2016. He had ST in October and November of 2015, in June and July of 2016, and in April through May of 2017. He shows improvement in most, but not all of his goals, but then deteriorates or loses function when the therapies end.

AS receives no LIDDA specialized services other than service coordination. Despite being very social, AS was never recommended or assessed for Independent Living Skills (ILS). He should also be assessed for Day Habilitation (DH) as he is of the same age as many people who enjoy DH. The nursing facility staff believe he would benefit from activities outside the facility and state that it "would be good for him to go to DH as he is in bed for most of the day except for Bible study and he might like it." The nursing facility staff stated that he has a new wheelchair but it does not appear that he received it through the PASRR process.

AS is not receiving a continuous program of active treatment, consistently implemented. He is not receiving any necessary specialized services, other than service coordination. With a diagnosis of cerebral palsy, it is very important that he remain as flexible, mobile, and strong as possible if he is to not suffer further contractures and loss of functional abilities. Given the improvement that was seen in the intermittent nursing facility therapies, it is clear that he would benefit from PASRR PT, OT, and ST. There is no carry-over of these therapies, and in fact, the nursing facility staff stated that he spends much of his day in bed. The nursing facility does not provide specialized training for serving people with developmental disabilities. He has not acquired the skills and behaviors which would enable him to function with as much independence and self-determination as possible. With the continued lack of appropriate therapies and specialized services, AS will continue to lose functional abilities.

AS does not have a professionally appropriate individual service plan (ISP). The plan is usually developed with only the service coordinator, one other person from the facility, and AS. The service coordinator has never contacted the family, including AS's sister M who is his LAR or obtained their suggestions or goals for AS, despite the fact that someone from the family is at the NF nearly every day and accompanies him on all medical appointments. For many reasons, AS's ISP is not a person-centered plan. The service coordinator stated that he has never spoken to anyone in the family. Despite his insulin dependent diabetes, glaucoma, dysphagia, and cerebral palsy, the ISP has very little information in the areas of clinical, medical, adaptive behavior, or nutrition. The service coordinator conceded that he was unaware of important medical information regarding AS such as AS being evaluated and found to be at high risk for aspiration and a recent hospitalization due to complications resulting from his diabetes. The assessments performed by specialists, such as PT, OT and ST, are not part of the ISP. The information frequently consists of just one or two sentences and does not provide a picture of who AS is and what his strengths, preferences and needs are. There are only two outcomes for AS to achieve: 1) to continue living at the nursing facility and 2) to participate in social activities with his friends. These are the same as the outcomes for another individual reviewed and who has the same service coordinator. As a consequence, the ISP is not individualized to AS or accurate and does not provide the framework for the acquisition of skills and behaviors that would enable him to have as much self-determination and independence as possible.

The ISP does not include goals for transition to the community, or address strategies to remove any barriers to community living. There is no description of what the community would look like for AS and Section 9, Phase II was left blank. Further, the goal that AS will continue living in the NF is inconsistent with the wishes of AS's LAR.

AS would benefit from living in the community. He has spent most of his life living with his family, first his parents, then with his brother, and then with his sister. His sister B stated that his sister M would like him to come and live with her but that she needs additional support. M is hoping to move closer to the rest of the family in Waxahachie and be able to have him come and live with her. The nursing facility staff also feel he would benefit from living in the community. The service coordinator also said that he could live in the community with appropriate supports and services. AS's needs could be met in a community setting with appropriate, 24-hour staffing support such as in a group home. He could also reside in a host home with additional in home personal care support.

AS had not made an informed choice to remain in the nursing facility. The service coordinator stated that AS is "perfectly content" and that the family wants him here. This is despite the fact that his sister Bertha stated that they are "not pleased with the NF and are "very unhappy". But no efforts have been taken to present AS individualized options for community living in a developmentally appropriate fashion. He has not been offered the opportunity to visit the community, and potential barriers have not been identified and addressed. The service coordinator has never spoken with the family so he is unaware of their hopes that he can return to the community and hopefully, live with family once again. Since coming to the nursing facility, AS has had very little exposure to community activities, outside of those with his family and minimal involvement in activities within the nursing facility. He has not had many community experiences in more than four years and neither he nor his family has experienced the range of supports that are available to person with AS strengths, needs, and preferences.

Individual: WD

Fort Worth, Texas Review Date: August 21, 2017

WD is a sixty-six-year-old gentleman who resides in a locked unit at a nursing facility (NF) in Fort Worth Texas. He was first admitted to this nursing facility in 2001. It appears that he lived with family until this admission. It is not clear where he lived between 2001 - 2004, after spending time in a psychiatric hospital. He has been at this nursing facility since April 21, 2004, except for one psychiatric hospital stay. WD is not legally competent and has a court appointed guardian through Guardian Services, Inc. (GSI) of Fort Worth, Texas. The guardianship was granted in January 2001 and will expire in 2018.

I first met with WD's guardian and the director of the guardianship agency, the service coordinator, and some of the nursing facility staff. The guardian expressed some concerns about my meeting alone with WD, so I agreed to meet with WD in the Assistant Director of Nurses' (ADON) office and in her presence. WD is described as having a close relationship with the ADON, although not as close as with the facility social worker, who was not working that day. The guardian stated that WD can be very fearful of strangers and changes in his routine. He has schizophrenia and paranoia and will express a fear of being sent back to "school," which he perceives as a very frightening place.

When I met with WD, he was very talkative and articulate. He seemed relaxed and answered all of my questions in considerable detail. He told me he went to school, and described it as a good experience. He was neat, clean, and well groomed. WD has a persistent hand tremor that could be a result of his psychotropic medications. WD went to a regular high school and graduated in 1969. He said his favorite subject was chemistry and that he ran the 50 and 100 -yard dash. WD likes to play checkers, dominoes, and other board games. He also loves music and singing in the choir. He likes to dance and will dance in the hallway of the facility. WD likes to go out to eat with the facility social worker to Red Lobster or Golden Corral. He goes to church every Sunday with a friend from the church. He has a high school friend here in the facility, and they spend time together. WD also enjoys stock shows and going to the park.

WD will talk about his parents as though they are not deceased. He can become quite upset and believe people are coming to get him and to kill him. Staff report that he has hallucinations and will have outbursts, but he usually can be redirected. He cycles through these episodes and has "good days and bad days." On his bad days he will often chose to isolate himself and spend time alone in his room on the locked unit. The ADON stated that when he first came in 2001, he was catatonic and he was also hospitalized at a psychiatric hospital about three years ago.

The ADON said that at one point WD's brother and his brother's wife were both in the facility, but he has now lost touch with them. WD does not see his family nor do they contact the facility or service coordinator.

WD is currently placed on the locked unit of the facility and has been there at other times. The NF staff state he is there because he wanders and because it is quieter and less stimulating. When asked about the criteria and process for admission to the locked unit, the staff said it is for safety, although the Director of GSI, who is the supervisor of WD's guardian, stated that she – not the nursing facility staff -- decides if he stays on the locked unit. WD is able to leave the unit during the daytime, upon request, and is usually out in the facility. WD sleeps on the locked unit at night.

WD did not have a comprehensive functional assessment of all of his habilitative areas that accurately identifies all his individual strengths and needs. He did not have an assessment of sensorimotor development, affective development, or social development. He had a PASRR evaluation (PE) on June 18, 2014 that was positive for mental illness and intellectual disability (ID). The PE recommends specialized services of service coordination, physical therapy (PT), occupational therapy (OT), speech therapy (ST), and durable medical equipment (DME). It also indicates that he had been admitted to a psychiatric hospital in the last two years and that he is not expected to return to the community, but will remain in the nursing facility. WD did not have a nutritional assessment until May 2017. He did not have a PT assessment until February 2016. He had OT at some point in 2015, but then was discharged from OT in November 2015. He had multiple MDS screenings and nursing care plans. The MDS are conducted by a registered nurse and are current.

WD is not receiving all necessary specialized services. He received PT, through PASRR, from February 29, 2016 until October 5, 2016. WD improved in his mobility and met and exceeded his short-term goals, but not his one long-term goal of complete bed mobility. He is ambulatory, although he remains a fall risk. The PT department has stated that he can return to PT at any time, but has taken no action to initiate or implement a therapy plan. WD would benefit from ongoing PT to achieve his long-term goals and prevent any deterioration of functioning. WD received OT services for some time in 2015, but then was discharged on November 24, 2015 for refusal to participate.

WD sees a counselor twice a week and a psychiatrist semi-annually for his psychiatric and behavioral needs. The counseling service is meeting his needs since it is frequent and on-going and focusing on the behavioral symptoms of his mental illness.

The only LIDDA specialized service that WD is receiving is service coordination though he would benefit from day habilitation and Independent Living Skills (ILS). His guardian has refused day habilitation services, because it is out of his normal routine and he is active within the nursing facility. The nursing facility staff agree that WD would benefit from ILS, however, he is not receiving these services. WD has shown that he can form close attachments to people through his friendship with the ADON and social worker. He has the potential to also trust a skilled ILS staff person. He enjoys going out of the facility and the ILS would afford him additional socialization and training activities. Interestingly, his guardian, GIS, refused OT, PT, ILS and Day Hab at his May 3, 2017 SPT meeting. It is not clear why the guardian does not feel these services would benefit him, given comments from the nursing facility staff and my observation of his skills.

WD is not receiving a program of continuous active treatment of specialized services, consistently implemented. The staff of the facility are not specifically trained to work with people with IDD and there is no carry-over of his activities. He is not receiving community-focused ILS that would facilitate the acquisition of skills enabling him to function with as much self-determination and independence as possible. He has shown that he enjoys being active and going out to the community. Currently, WD is entirely dependent upon the nursing facility for all of his outings and they are not able to ensure that he goes out frequently.

WD does not have a professionally appropriate Individual Service Plan (ISP). His ISP has only two outcomes: 1) to continue going to church in the community; and 2) to continue to go out to eat with the social worker and attend music activities. He has indicated that he has several other interests, such as music and dancing, and he should have more goals that explore his strengths and preferences. His abilities enable him to achieve more growth and these goals, while positive for him, are the same goals that he has had for several years. Although the ISP is thorough and contains a lot of information regarding WD, it is not a person-centered plan because it contains no information on his preferences or needs in the community. Phase II of Section 9 is left blank.

WD would benefit from living in an integrated setting with appropriate community supports and services. He is capable of much of his self-care needs and his medical condition is similar to those of many people who live successfully in the community. He lived in the community for much of his life. However, he is described as content to be in the facility, in large part because of his relationship with two of the staff who provide him with support to manage his mental illness. He has been in this facility for most of the time since 2001, so he is very familiar with the routines and environment. His guardian is very firm that WD must remain in the nursing facility, and WD, while articulate, does not express a desire to leave the facility.

WD's guardian has made an informed choice for WD to remain in the nursing facility. The service coordinator has presented the Community Living Options (CLO) on a regular, semi-annual basis. Barriers have been identified and potential solutions are outlined, including offering to take the guardian and WD on community visits. The guardian service, GSI, including the three different guardians over the past two years, have consistently refused community options and have decided that WD should remain in the facility.

Individual: SS

Copperas Cove, Texas Review Date: August 17, 2017

SS is an 80-year-old woman who lives at a nursing facility in Copperas Cove, Texas. She has an unspecified intellectual disability and has lived at the nursing facility since at least 2002. Prior to her admission to this nursing facility, SS lived in a private home in Killeen, Texas. When I met with SS, she was sitting in her wheelchair, pulled up to a table in the dining room; she was very conversant and friendly. She said she likes to be active and would like to go outside, to go to the library, or to the store to buy make-up. While the nursing facility has regularly scheduled trips into the community SS is unable to participate as they cannot transport her wheelchair. SS has no opportunities to leave the facility. She likes to put on make-up and can brush her hair. She showed me her room and her coloring book and word search book. She has a purse she carries with her that is full of crayons and pencils. The staff report that she likes to be active and is typically out of her room.

The nursing facility staff report that SS's health is currently stable after recovering from a considerable number of health complications in the recent past. In 2015 and 2016, she had multiple complications from knee surgery – including three surgical debridement procedures – suffered kidney failure, contracted sepsis including MRSA, developed a urinary tract infection, and was placed on hospice. She was hospitalized a total of six times from April 2015 to June 2016, and had two additional emergency room visits through September 2016. SS also has diabetes requiring insulin, but her diabetes is currently under control.

SS has not received a comprehensive functional assessment of all her habilitative areas that accurately identifies her individual strengths and needs. She has not had assessments in the areas of auditory functioning, cognitive development, social development, and adaptive behaviors. She had a PASRR Level 1 done on April 17, 2013 – at least eleven years after her admission – that was positive for IDD. She had a PASSR Evaluation (PE) done on August 18, 2014 that found she could walk and was independent in all areas of self-care, but needed some assistance with eating, taking medications, and nutrition. SS received another PE on March 2, 2016. She also received physical therapy (PT), occupational therapy (OT), and speech therapy (ST) assessments, but they did not occur until late 2016 and not at the same point in time as other assessments. She has a nursing care plan, which details her medical/nursing needs, and finally had a psychological evaluation in 2017. The assessments done for her have been done over a period of several years, during which she had major changes to her health and functioning, were not done as part of a coordinated, collaborative effort, and do not present a cohesive and comprehensive picture of SS' needs and strengths.

SS is not receiving all necessary specialized services, even though she needs these services to improve her functioning and avoid regression. Her PASRR Quarterly Review in May 2016 recommends specialized services of OT, PT, and service coordination. Her PASRR Quarterly reviews of September and November 2016 and February and April of 2017 recommend only service coordination, and deleted all other services. She received time-limited rehabilitative OT and PT in the fall of 2016. In December 2016, she had therapy evaluations that concluded that no therapies were indicated, even though she was recovering from a series of knee operations subsequent to her knee fracture in April 2015, which ordinarily would have required ongoing PT. She finally began receiving OT and PT, again time-limited, in March of 2017. She continued with Medicare-funded OT until May 2017, when she began receiving it through PASRR, with a certification to continue the service through September 2, 2017. She continued to receive time-limited PT until July 2017, when she finally began receiving it through PASRR, with a certification to continue the service through August 25, 2017. Therapy records indicate that even though SS was expected to receive habilitative OT five per week and PT three times per week, she received only two OT visits in August 2017 for a total of 46 minutes and received only one PT visit in August 2017 for a total of 30 minutes. The facility's rehabilitation director told me that confusion about whether these services received recertification approval from the State prevented her from delivering the services as needed. She also received time-limited ST from March through May 2017. She finally began receiving ST through PASRR in May 2017 and is certified to September 3, 2017. As part of the ST, she received a dysphagia evaluation, which found she did not have any signs and symptoms of aspiration. SS also received psychological counseling, five times since January 2017.

She would benefit from the continuation of habilitative therapies. Once SS began to heal from her surgery in the fall of 2016, therapies should have been initiated to begin the process of regaining as much of her former skills as possible. The intermittent, and at times absence of, these therapies had a deleterious effect on her mobility. Today, she is dependent upon a wheelchair, even though she desires to walk again. She is an active participant in the therapies that she is finally receiving. She would also benefit from a customized manual wheelchair (CMWC) since it is likely she will need one, at least for distances, for the foreseeable future.

Although she would benefit from Independent Living Skills (ILS), the only LIDDA specialized service SS receives is service coordination. ILS is necessary to prevent loss of skills in SS, as she likes to be active, has a need for additional skill development, and has many interests. She has consistently said that she enjoys shopping, and participating in community events, yet is confined to the nursing facility.

SS is not receiving a program of continuous active treatment of specialized services, consistently implemented. Until recently, she was not receiving virtually any needed therapies and still is not receiving any community activities or services that she needed to regain her ability to walk and her previous independence. She is not receiving services that would assist her in accessing socialization and learning independent social and recreation skills through ILS. The staff of the nursing facility are not specifically trained to work with individuals with IDD. She has lost skills since her PE in 2014 and did not consistently receive therapies until the spring of 2017. Due to the lack of a wheelchair van at the nursing facility, she has no way of accessing the community, despite her love of going on community outings. Socialization is important to her, yet she has lost access to integrated social settings because she is not able to leave the nursing facility.

SS does not have a professionally appropriate, person-centered Individual Service Plan (ISP) that is based on her strengths, needs, and preferences and that includes strategies for addressing barriers to community living. Her most recent ISP, dated July 27, 2017, lists only one outcome for SS: to attend activities of her choice. Barriers to community living are not identified in the plan, and resolutions are not proposed. The most recent quarterly review does show that she is finally receiving some therapies and details her medical/nursing concerns. However, this single outcome is limited in that it does not address new skills and preferred choices, as well as community activities, since she is prevented from leaving the nursing facility because of her immobility and lack of a wheelchair van. Some of her preferred activities are to go outside and to go shopping, both of which are denied to her. She does not have outcomes that would help her acquire the skills and behaviors to be more independent and to increase her self-determination such as her preferences for purchasing wanted items. Her ISP is primarily medically-based and does not discuss barriers to community living.

SS's service coordinator informed me that SS cannot leave the nursing facility because of the lack of a wheelchair-accessible van, which is a barrier that impacts all residents of that nursing facility. But the facility's rehabilitation director made clear that SS could manually transfer to a vehicle and could be transported to community locations without an accessible van. SS has been confined within this facility for years, mostly due to the mistaken belief that she cannot leave without an accessible van, which is not available to her.

SS would benefit from living in an integrated setting with appropriate supports and services. Prior to her admission to the nursing facility, she lived in the community. Until 2015, when she fell and fractured her knee, she was fairly independent and could have lived in the community with moderate supports. She remains interested in being active and is working in her therapies to regain as much of her mobility as she can. Her needs are similar to many people who are successfully served in the community, who have much more frequent opportunities to socialize with family and friends and participate in activities of their choosing.

SS has not made an informed choice to remain in the nursing facility. Although SS expressed an interest in exploring community options, she has not been able to visit any community programs, participate in ILS activities in the community, or go on community outings simply because she uses a wheelchair. When I asked the director of rehabilitation services if SS could ride in a regular car, she said she felt she could; and yet no one has suggested this potential solution to resolve one of the barriers to accessing the community. Section 9 phase 2 of her ISP is not filled out and neither her ISP nor the CLO process describes what the community would be like for SS, including where she might live, who she might live with, what she might do, and how her needs and preferences could be met. The limited information provided to her is not tailored to her cognitive abilities, does not provide choices that she can understand, and, most importantly, is not designed to engage her in a conversation about community living. The one barrier identified "She does not want to live in the community," is not consistent with the findings of this review and regardless, no effort has been taken to address this potential barrier.

During the first 12 or so years of her stay in the nursing facility, SS was fairly independent and could have lived in the community with moderate supports. These last 15 years of her life cannot be lived over, but she could be provided with the opportunities to investigate community options, including ILS services, and have a more active life of her choosing.

Individual: BH

Stephenville Texas Review Date: August 23, 2017

BH is a seventy-year-old woman who resides at a nursing facility in Stephenville, Texas. The nursing facility staff with whom I met told me that they believed that BH was admitted on August 11, 2004, although nursing facility staff say she may have been there longer. The staff said she had been hospitalized at a state hospital and has a long history of other hospitalizations in Kansas, New Mexico, and Texas. Without prompting, BH recounted that she doesn't know why she was hospitalized. She said she was bouncing a ball on the sidewalk "minding my own business" when she was taken to the hospital, tied to a bed, and then moved to a jailhouse. She said she had four boyfriends and recalled their names. This perception of how she left her home is something she has recounted several times in her record. It appears quite likely that she did not choose to leave the community. The nursing facility staff do not believe she ever lived in a group home setting, but think she might have been at one of the state supported living centers.

BH has at least two brothers, one of whom was at the state hospital with her and also lived at her current nursing facility. He is no longer at the facility. She has another brother with whom she had lost contact for a number of years, but due to a fortunate series of events, the two made contact during a hospitalization. This brother, JH and his wife are very involved with her and visit weekly. Her brother is her LAR.

When I met with BH, she seemed to be perpetually in movement, with a number of hand movements, brushing her hair back from her face and tic-like mannerisms that she kept repeating. She spoke quickly, somewhat quietly, but attempted to answer all questions. After conversing for ten or fifteen minutes, she got up and waved goodbye to me. Staff report that BH is generally active at the facility and participates in many activities. She especially likes arts and crafts, coloring, bingo, parties, music, and outings. She loves jewelry and karaoke. There are times when she will become irritable and not participate in activities, preferring to stay in bed, but these periods pass fairly quickly. She has a past history of serious sexual abuse. She has diagnosis of congestive heart failure and atrial fibrillation, seizure disorder, bipolar disorder, hypothyroidism, dysphagia, GERD, and impulse control disorder. She has not had a seizure in a very long time and she takes a blood thinner for her cardiac disease which they describe as stable. Staff report that she is doing well although she has an unsteady gait and has fallen on several occasions. The Physician Order Report of July 7, 2017 states that she has a history of falling, muscle wasting atrophy, and muscle weakness.

BH did not have a comprehensive functional assessment of all habilitative areas. She did not have assessments done in the areas of nutritional status, affective development, auditory functioning, cognitive development, social development, and adaptive behaviors. She had a PASRR evaluation on May 29, 2015, more than ten years after her admission, which affirms IDD only. The only specialized service recommended is service coordination. She has had multiple MDS assessments, with the most recent one done on June 10, 2017. She had nursing facility assessments for physical therapy (PT) at least as early as August 2015; for occupational therapy (OT) as early as June 2015; and for speech therapy (ST) as early as August 2015. She had a psychological evaluation as early as June 2015. She has a nursing care plan that is current. These various facility assessments all take place over a significant period of time after her admission to the facility and are not done in collaboration as part of a team. Much of the focus of the assessments is on her medical/nursing issues.

BH is not receiving all necessary specialized services. She is receiving service coordination although there have been three different service coordinators in the last two years. It is not clear who is her current assigned service coordinator. She is not receiving any nursing facility specialized services now, even though she would benefit significantly from habilitative PASRR OT, PT and ST and they were recommended by her service coordinator as far back as 2016. While she did receive rehabilitative OT, PT, and ST, it was intermittent and she experienced a loss of skills between sessions. She had PT in August through September in 2015, from September through October in 2016, and in February and March of 2017. Each time she worked on the same goals of dynamic standing balance, standing mobility, safety navigation, following two step directions, and bilateral lower extremity strength. She progressed and met her goals, the therapy stopped, and then had to be restarted many months later after her skills and functioning had deteriorated. She has an unsteady gait and has fallen, due in part to the termination of PT. This pattern is similar with ST, with services in August through October in 2015; again in February through April in 2016; in September and October of 2016; and in June and July of 2017. She worked on dysphagia therapy and increase in problem solving to increase her self-care skills. After the services were terminated, she showed declines of weight loss, self-care skills, and safe swallowing. OT services were provided along the same time frames as PT and BH worked on hygiene and grooming, bilateral upper extremity strength, and upper body dressing in order for her to participate in as many activities as possible. All these services were provided intermittently, and were not the habilitative PASRR therapies that would have helped her to retain her skills for independence and self-determination. Since my review, BH has fell on August 31, 2017, breaking her hip and requiring surgery.

BH is not receiving any LIDDA specialized services except service coordination, even though her nursing staff believe she would benefit from Independent Living Skills (ILS). She likes to be active and participate in activities at the facility. The one-on-one companionship from a staff person trained in working with people with IDD would increase her independence and socialization skills. She is receiving psychological services through the nursing facility, but if this does not continue she will require LIDDA behavioral supports. She shows variation in moods with some difficulties in participation and her medications are monitored and changed as necessary.

BH is not receiving a continuous program of active treatment, consistently implemented. She did not have a comprehensive functional assessment which would form the basis for her specialized services. She is not receiving services that would promote her independence and self-determination. She is not receiving the therapies she requires on a consistent basis; instead, they are intermittent and solely for rehabilitative purposes, rather than for habilitation. Staff at the facility do not receive special training in working with people with IDD. She does not receive continuous active treatment across settings, such as community outings, that would enable her to acquire skills toward independence. For example, she has a problem with impulse control which causes difficulty in focusing in her therapies and yet the counseling sessions do not work in concert with her therapy team to mitigate this challenge.

BH does not have a professionally appropriate Individual Service Plan (ISP). She did not have a comprehensive assessment which would inform the planning process and result in a plan that is individualized to BH. The ISP is not person-centered for several reasons. The plan does not contain any outcomes for BH to achieve; she is not working toward gaining any skills that would increase her independence and self-determination. There is very little information that discusses her strengths, needs and preferences. The primary focus is on her medical/nursing services. Other than service coordination, she does not receive any of the specialized services from the LIDDA that she needs and that would allow her to increase her independence. Her ISP does not include a transition plan which discusses barriers to community living, there is not a description of what the community would look like for BH, and Section 9 Phase II is blank. She did not have the required quarterly team meetings during 2016, as reflected in her ISP. Her initial SPT team meeting was held a year earlier, on September 2, 2015 and there were no quarterly meetings thereafter.

BH would benefit from living in an integrated community setting with appropriate supports and services. She is fairly independent in her self-care skills, but she would require 24-hour staff support. Her medical condition of atrial fibrillation can be managed in the community as is currently done. Although she has a history of institutionalization, this is not a justification for continued institutionalization. She would benefit from ILS services in order to establish rapport with someone who could introduce her to community activities and allow her to gradually engage with different activities and spend time with non-disabled peers.

BH has not made an informed choice to remain in the nursing facility. While she has expressed that she does not want to live in those “old crazy” group homes, and that ‘she does not want to move back to those “darn hospitals”, she has not had the opportunity to learn about community options, to visit community programs, or to understand the difference from her previous living situations. Her history of abuse requires that she have a consistent relationship with a limited number of individuals in order to trust another person; the turnover and inconsistency with service coordination has impeded her understanding of community programs. The lack of ILS has also made it more difficult for her to understand the benefits of being in the community, even for minor events such as purchasing items at a store. Her past of history of institutionalization and abuse has left her fearful and mistrustful and unwilling to explore options beyond the nursing facility.

CLO meetings to provide information about community services do not occur as required -- she had only one CLO meeting in 2014, two in 2015, one in 2016, and one in 2017. There is no indication that BH has ever been exposed to community services, allowed to visit a community program, been presented with developmentally appropriate information about individualized community options, or made a meaningful choice about community living.

Individual: SH

Austin, Texas Review Date: August 14, 2017

SH is a 70-year-old gentleman who was admitted to a nursing facility in Austin, Texas on September 7, 2016. He is very articulate and easily responded to all of my inquiries. He described in considerable detail what is important to him and what his hopes are for the future. SH is divorced and is close to his cousin, who has a limited power of attorney. SH is legally competent to make his own decisions and eager to resume his previous life.

Prior to his admission to the nursing facility, SH lived on his own, in Bent Tree Apartments with his dog. He was active in his community, able to care for himself, and very involved with his church. He was able to walk without a walker or cane. When he lived in his own home, he had Section 8 housing and Meals on Wheels. With these supports and those of his family and community, he was happy living in his apartment and has repeatedly expressed that is where he wants to be again. He readily discussed that he is a recovering alcoholic with 21 years of sobriety. He has a developmental disability, cerebral palsy, and seizures, although he has not had a seizure in 15 years. He does not have an intellectual disability.

SH reported that his admission to the nursing facility was triggered by his difficult, post-operative recovery after triple bypass surgery and heart valve repair on August 24, 2016. He had a difficult recovery at the hospital, experiencing lack of oxygen (hypoxia) and collapse of his lung (atelectasis). It appears that he also had a stroke with paralysis, and now has some left side weakness. He had a cardiac pacemaker implanted on August 29, 2016. He has some short-term memory loss. This difficult recovery in the hospital continued into the nursing facility. He had a series of falls in September and October of 2016 and January and February of 2017. He went through a period of mental confusion in which he was resistant, delusional, and required assistance with his ADL needs. The MDS nurse noted in December 2016 the need for a neurological assessment because she felt "something is not right for him." This period of mental confusion lasted from his surgery in August 2016 until early March 2017.

SH has not received a comprehensive functional assessment of all his habilitative areas that identified his strengths and needs. He did not have assessments in the areas of affective development, auditory functioning, cognitive development, social development, vocational skills, or independent living skills. Despite the diagnosis of cerebral palsy, he had a Level 1 PASRR screening on admission that failed to identify any intellectual or developmental disability. He had another PASRR Level I screening on December 19, 2016, more than three months after admission, that concluded SH had a developmental disability. He had a Level 2 PASRR Evaluation on December 21, 2016, which noted he was appropriate for community placement. Although SH received assessments for PT, OT, and ST, they were done at various intervals over several months during his NF stay, were not coordinated, and were not part of an interdisciplinary team effort. In addition, the assessments did not consider SH's previous high level of functioning nor his repeated statements that he wanted to walk again and return home. The assessments repeatedly describe him as refusing to participate in therapies, despite SH asking for assistance and treatment. The assessments also fail to recognize the significant change in his mental functioning ability and the impact that had on his ability to participate. Despite the very difficult medical events he has been through, his assessments do not address the impact of the lack of oxygen, his collapsed lung, and his stroke after open-heart surgery.

SH is not receiving all necessary specialized services, even though he could benefit from and needs these services to maximize functioning and avoid deterioration. SH's PASRR evaluation recommended service coordination, physical therapy (PT), occupational therapy (OT), and durable medical equipment (DME). SH has not consistently received any nursing facility specialized services. He has received OT, PT, and ST as rehabilitative interventions and only on a time-limited, intermittent basis. His OT, PT, and ST services began in September 2016, but were very intermittent until approximately May 2017, when his mental functioning improved and he was able to participate in different therapies. At his January 2017 Service Planning Team (SPT) meeting, no specialized services at all were recommended except for service coordination, even though one month earlier the PE recommended numerous specialized services. PT notes repeatedly state that SH has "reached a plateau," despite his continued statement that he "needs to build [his] stamina and relearn how to walk." Moreover, specialized services of OT and PT are particularly appropriate given the fact that that he suffered at least six falls in a four-month period between September 25, 2016 and February 2, 2017. When I visited SH, he stated that he is now able to walk with a walker. He stated that even though he isn't receiving PT, he tries to improve his functioning on his own by making sure he walks up and down the halls and lifts two-pound weights.

SH receives no LIDDA specialized services other than service coordination and alternate placement planning. Despite the recommendation of his Service Planning Team at the January 5, 2017 team meeting, he did not receive PASRR behavioral services, although he did receive Medicare mental health services beginning in September 2016. SH indicated that he would like to participate in Independent Living Skills (ILS) to help him in his quest to return to his apartment living. Significantly, specialized services would have helped SH return to his previous skill level much earlier and quicker, and to resume his prior ambulatory ability and independence in ADL skills through continuous and consistent services. There is no reason why they have been discontinued, forcing him to work on gaining skills on his own and in the face of his fear of falling.

SH is not receiving a program of continuous active treatment of specialized services, consistently implemented. As noted above, other than service coordination he did not receive any of the recommended habilitative specialized services in his PASRR Evaluation, until alternate placement planning began at the end of February 2017. An error in sending out the wrong Section 8 form delayed approval for returning to his desired apartment building. His lack of specialized services and the intermittent nature of his rehabilitative services has seriously impeded his ability to acquire the necessary ADL, mobility, and mental functioning skills to be as independent as possible. He regressed significantly from his pre-operative condition and made very little progress until late February/early March 2017. Active treatment services were not delivered consistently across all settings, since nursing staff were not trained on working with individuals with developmental disabilities. Active treatment of continuous specialized services would have provided him the support he needed to recover from these very challenging events.

SH does not have a professionally appropriate Individual Service Plan (ISP). His most recent ISP is dated January 5, 2017 with a SPT meeting held on August 15, 2017. The ISP is current in the discussion by the team and the goals for SH to 1) Use his walker more; and 2) Move into his own apartment. Section 9 shows that he wants to pursue community living and lists one barrier with a possible resolution. While Phase II has information regarding the supports SH will need in the community, it is not a complete plan and does not describe the residential setting, day or vocational activities, medical services, personal assistance: Activities of Daily Living, specialized transportation, and any specialized training for the caregiver. SH should be assessed for these supports in order to successfully transition to the community. SH has been consistent in stating that he wants to return to his previous apartment complex utilizing the Section 8 voucher which he previously had for 8-10 years. The team completed the PA Application for the Section 8 voucher at this meeting but he continues to wait for the system to respond to his desire to return to the community.

It is very clear that SH would benefit from living in an integrated setting with appropriate community services and supports. He was able to live on his own for his entire adult life, had a large group of friends, and would once again enjoy the benefits of self-determination and independence. In a more integrated setting, SH was able to engage in numerous activities that were important to him but have been curtailed or impeded during his nursing facility stay. These included, among many things, maintaining his relationships with family and friends, participating in religious activities, and attending recovery supports for his past alcoholism.

SH has made an informed choice to return to the community. SH's PASRR Evaluation of December 2016 inaccurately states that he does not want to return to the community, which is directly contradicted by multiple statements that SH has made, and continues to make, during his nursing facility stay. Despite the fact that he successfully lived in the community for his entire adult life, it was determined that, as a result of a rather common though serious medical procedure, he would want to spend the rest of his life in a nursing facility. He consistently stated that he wanted to return to his apartment, as early as September 2016 and continually at meetings up to the present. He repeatedly expressed his preference to leave in therapy sessions, beginning in the fall of 2016 when he had a great deal of difficulty concentrating. He was very clear during my interview that he wants to return to an apartment at the Bent Tree complex and recognizes that he will need supports to assist him. The team is now working to assist him with his oft-stated wish to return to the community. However, he has not been offered information about other community options and the services necessary to support SH have not been identified. SH is very articulate, is aware of what he has gone through since his surgery, and recognizes that he will need additional support. Although his service coordinator is working with him to assist him in returning to that life and arranging the necessary supports he will need including Section 8 housing, Meals on Wheels, a Metro Access card, and coordinating with the nursing facility social worker, SH does not have a comprehensive transition plan. It is wholly inappropriate and actually harmful that SH was not able to receive the specialized services of OT, PT, Behavioral Health, and ILS which would have enabled him to return much sooner than a year after admission to the nursing facility.

Individual: BF

Stephenville, Texas Review Date: August 23, 2017

BF is a sixty-six-year-old woman who resides at a nursing facility in Stephenville, Texas. She was admitted on November 1, 2016 from a private intermediate care facility for people with intellectual and developmental disabilities (ICF/IDD). She said she came to the nursing facility because it was time to “retire” and that she is old (65 at time of admission). She lived at, and enjoyed, the group home for over thirty years. BF is legally competent to make her own decisions.

I met with BF in a sitting area at her nursing facility. BF was very conversant and was responsive to my questions. She smiled frequently and seemed to enjoy my visit. At the time of our meeting, BF was sitting in a wheelchair. She said she could stand up from her wheelchair and could do exercises with her hands and arms. She told me that she had just been to therapy where she brushed her teeth, practiced walking, and threw balls. She said she likes to stay busy and play bingo (even though they don’t give prizes), ride in the car, go to her sister’s house, and attend church. BF also said that she enjoys coloring in her coloring books and drinking soda. She remembered the names of all of her housemates at the ICF/IDD, and said she would like to see them again. She said she likes to read, and that English was her favorite subject in school. BF said that she enjoyed attending a day habilitation program when she was living in the community, but had not been provided the opportunity to attend a day habilitation program since her admission at the NF. She said she would like to attend a day habilitation program with other people her age.

At her Individual Service Planning (ISP) meeting of September 16, 2015, the year before her admission, BF’s interdisciplinary team asked her primary care doctor to “write orders for nursing home placement?” The LIDDA staff who I interviewed said that the group home staff where BF was residing made the referral for her to move to the nursing facility, but it was the family who, though not authorized to make decisions for BF, decided to move her. But when I spoke with BF’s sister, the sister insisted that the group home told her that they could no longer meet BF’s needs and urged her “to retire and go to a nursing facility.” BF’s sister said that she is planning to return to the Longview area of Texas from Louisiana, and plans to move BF from the nursing home to an appropriate community placement.

BF did not receive a comprehensive functional assessment of all her habilitative areas that accurately identifies all her individual strengths and needs. BF also did not have any assessments in sensorimotor development, cognitive development, social development, adaptive behaviors or vocational skills. She had a PASRR Level 1 on 10/14/16 and 10/28/16, both prior to her admission, but no effort was made to divert the admission or identify another appropriate community placement. The first evaluation determined that BF had intellectual disabilities (ID), developmental disabilities (DD) and mental illness (MI) and the second evaluation also found that she had ID, DD, and MI. BF had a PASRR Evaluation (PE) on 10/28/16, prior to admission, which confirmed that she has ID, DD, and MI and recommended specialized services of alternate placement, service coordination (SC), occupational therapy (OT), physical therapy (PT), and durable medical equipment (DME). Although BF received PT and OT in the community prior to her admission to the facility and the PE recommended that she receive these specialized services, BF did not have a PT evaluation until the end of December 2016 and still has not had an OT evaluation. BF had a nutrition evaluation by a registered dietician on November 1, 2016, and nursing assessments regarding her medical care needs and other health and self-help needs. However, these assessments were not part of a collaborative process at one point in time to address her current status and provide the basis for developing her ISP.

BF is not receiving all necessary specialized services. She is receiving no nursing facility specialized services despite the recommendation of OT and PT in her PE, and despite the fact that she was receiving them in her community program. In her SPT meeting of September 16, 2015, to discuss her potential discharge from the community program, the team states “B will need to continue with her OT and PT to maintain her mobility along with walking at the DH five days a week.” She began receiving rehabilitative PT on December 28, 2016, but it was only continued until February 8, 2017. In part due to a lack of PT, she is no longer routinely walking, but is using either a walker or a wheelchair. There has also been a recommendation that BF receive durable medical equipment (DME), but it is not clear what type of equipment she requires.

BF is receiving no LIDAA specialized services other than service coordination. She would benefit from Independent Living Skills services (ILS) and told me that she would enjoy that very much. She likes to be active, but virtually all of her activities take place within the nursing facility. She no longer has Day Habilitation (DH) services despite having had them right up to her discharge from the community program. At her SPT meeting of September 16, 2015 the team states “It is important for B to continue working on all contracts provided at the Day Hab to encourage socialization with her peers, staff and to gain her personal spending money.” They also stated, “It is [important for B to] continue training objectives regarding her physical, therapy … and exercise program.” When asked, BF said she would like to go to a program where there were people her own age, such as an Adult Day Habilitation program. There has also been no effort to implement the recommendation for alternative placement, and no transition planning has been considered. And although BF is receiving service coordination, she has just been assigned her third service coordinator since September 2016. Building a relationship with an individual is challenging with this number of different people in her life, someone she sees generally once a month for a brief visit. According to the records, she did not receive any service coordination visits from February 20, 2017 through September 1, 2017.

BF is not receiving a program of continuous active treatment of specialized services, consistently implemented. She is not receiving all of the necessary specialized services that will enable her to maintain the skills and behaviors that allow her to function with as much independence and self-determination as possible. It appears she has already lost skills in ambulation and the lack of PT, OT, and day habilitation is in direct contraindication of the recommendations of her SPT team at her last community based ISP. The staff of the nursing facility do not receive specialized training in working with individuals with IDD. The Director of nursing did not understand BF’s basic rights as she initially refused to allow her to visit with me.

BF does not have a professionally appropriate ISP, based upon a comprehensive functional assessment which includes all needed services and supports for BF to successfully transition to the community. Her most recent ISP in September 2015 pre-dates her admission to the nursing facility and does not meet the standards of active treatment. The ISP is not a person-centered plan for several reasons. The plan has only three outcomes: 1) wants to look nice; 2) wants to make money; 3) wants to be able to get around (PT/OT). The last two outcomes are not being implemented. She has no other outcomes that express her preferences or need areas such as her expressed desire to go out of the nursing facility for socialization and community outings. Although alternative placement is recommended in BF’s PASRR

Evaluation, the ISP does not identify potential barriers to transition and contains no individualized description of what the community would look like for BF.

BF would benefit from living in an integrated setting with appropriate community supports and services. She lived in a group home, an ICF/IDD, for over thirty years. She and her sister (PW) felt that living in the community and in that program was very positive, allowing her to participate in community activities and maintain her independence. BF's sister (PW) said that she plans to return to Texas and will have BF evaluated for a knee replacement to address her knee problems. She is also planning to move BF from the nursing facility and is considering community placement again. At the SPT meeting of 9/16/15 the team states, "She needs to remain in the HCS slot as she benefits from having her own private room and the ability to see her sister Holly and extended family members when possible." BF's move to the nursing facility was due to the program's perception that BF should "retire", but her abilities are very similar to many others who successfully live in the community. Paradoxically, those same abilities have continued to decline in the nursing facility and she is receiving fewer therapies than she did in the community to improve or maintain her skills, mobility, and independence.

BF did not make an informed choice to remain in the nursing facility. Her PE of 10/28/16 lists Alternate Placement as one of the LIDDA specialized services she requires. Despite this recommendation, the PE states that she does not expect to return to the community and her long term placement is the nursing facility. This is despite the expressed statement of her sister and the successful 30-year history of being served in the community. The SPT meeting of 9/16/15 also states "The HM, DHS and RN informed me that the RH HCS Program Manager is wanting her to move to nursing facility that could better serve her. The HM, DHS and RN also said that the Program Provider needed to move clients because four ICF consumers had received their HCS slot." This statement indicates that the program manager of the ICF/IDD had four other individuals who needed a place to live so BF was convinced that she needed "to "retire and go into a nursing facility". There is no indication in the records that BF has received any information about community living options or had the opportunity to visit potential community placements and there is no evidence that potential barriers have been identified and addressed. While it is true that BF was age 65 at that time, retirement is not equivalent with entering a nursing facility. Her decline in health was most likely due to a health problem that could have been successfully treated with a knee replacement.

Attachment A

Attachment A

Barbara T. Pilarcik
23 Apple Hill Road
Wilbraham, MA 01095
(413) 596-3555

Results:

Expanded services of The Association for Community Living through a merger with a family support agency, providing financial stability to those services and tripling their business. Agency services and financial stability increased through a 50% increase in agency budget, from $17 million annual budget to nearly $30 million annual budget in 7 years. Expanded adult family care model, autism services and services to individuals with complex medical conditions. Built 5 new fully accessible homes and ensured the successful passage of legislation that transfers state land and old 8 bed ICF/ID homes enabling the building of new 5 person homes. Developed and implemented a Leadership Institute providing leadership training to over 25 senior and middle managers.

Member of a national committee that obtained the successful passage of federal tax legislation clarifying that foster care provider stipends are excludable from federal income tax.

Testified as an expert witness in the *Rolland* law suit, resulting in hundreds of individuals leaving inappropriate placements in nursing homes for community residential settings.

Chair of the Complex Medical Needs Task Force, a collaborative project of the Department of Mental Retardation and the provider community. Obtained grant from the Massachusetts Developmental Disabilities Council and published a manual for providers, consumers, and their families to ensure smooth transitions from home to hospital. The manual has been requested by developmental disability providers throughout the US.

Developed and implemented an appeals process which resulted in successful resolution of 85% of client appeals for Region I, the Department of Mental Health.

Developed the first Human Rights Committee at Northampton State Hospital; set up the Human Rights Complaint system.

Resolved major management and quality problems at The Association For Community Living's ICFs/MR resulting in 5 years of "no deficiency" citations by the Department of Public Health.

Developed first community residential service for former Northampton State Hospital clients in Western Massachusetts.

Work Experience:

Consultant-current

Provide consultative services for expert witness in the field of developmental disabilities including litigation and quality reviews. Provide executive coaching, leadership development and clinical services and other skills necessary for the successful management of a human service agency.

Executive Director ***2009-2016***

The Association for Community Living, Springfield, MA

Responsible for overall operations and financial management of The Association, ensuring stability and growth. Included are planning and establishing priorities; developing and overseeing strategic initiatives, programs and The Association policies; building and maintaining relationships with constituents, funders and collaborators; and representing The Association on a local, regional and statewide basis. The Association has an annual operating budget of $30 million and serves over 1000 individuals and families in western Massachusetts. Services include residences, shared living settings, intensive foster care, family support, social-recreational, individual support and employment supports. The Association has approximately 600 employees.

Litigation Work:

- United States Department of Justice in Civil 1:10-CV-249-CAP, Georgia: 2015-current. Expert Witness.
- *Steward Interim Settlement Agreement;* United States Department of Justice and State of Texas; 2014-current.
- United States Department of Justice and Commonwealth of Virginia Settlement Agreement under *Olmstead*; 2012-current.
- Kotin, Crabtree and Strong, Boston Massachusetts
- *Evans* Court Monitor, Washington DC, June 2005-February 2016.
- Center for Public Representation, *Rolland* Law Suit: 1991-2003; expert witness for the plaintiffs in the class action lawsuit *Rolland vs. Cellucci.* Testified in federal court, gave depositions, and evaluated specialized services under Title XIX for members of the plaintiff class. Suit was settled through a consent decree, appealed and decided at the First Circuit in favor of the plaintiffs. Over 600 people were moved from nursing homes to community placements.

Director of Specialized Home Care and Intensive Residential Services ***1994-2009***

The Association for Community Living, Springfield, MA

Responsible for the direction, management and development of the two Divisions; establish program policy; manage program budget; negotiate contracts, develop liaisons and oversee the supervision and operation of all components in accordance with Association and external regulatory agencies' regulations, standards and policies. The two divisions provide residential services for 136 individuals with developmental disabilities; some of who have complex medical needs. The divisions' budgets are over $7 million with the supervision of approximately 200 staff and over 100 care providers. Negotiate with four state agencies in two states.

Interim Executive Director ***1/1993 – 4/1993***
The Association for Community Living, Springfield, MA

Responsible for the overall management of the agency during the search for the new Executive Director. Provided leadership, overall operation and financial oversight.

Director, Intermediate Care Facilities ***1985 – 1992***
The Association for Community Living, Springfield, MA

Responsible for overall management of ICF/MR programs for people with mental retardation and physical handicaps; member of agency senior management team; chair; Agency Reorganization Committee; President, Massachusetts Association of ICF/MR Providers (3 years).

Interim Executive Director ***1990***
The Association for the Support of Human Services

Assumed directorship of this agency in order to stabilize daily operations, direct search for new executive director; repair relationships with funding sources, and provide leadership while maintaining existing position at The Association. The Board of Directors presented an award for "Outstanding Consultative Services".

Appeals Mediator ***1981-1985***
Massachusetts Department of Mental Health

Developed and implemented mediation process for the resolution of client appeals pursuant to state regulations; evaluated the Department's implementation of Individual Service Plan process; monitored implementation of client rights' regulations; trained staff in Human Rights. Organized and maintained the first Human Rights Committee at Northampton State Hospital. Conducted investigations of serious allegations at state facilities. Prepared depositions for Roger's hearings and monitored Roger's orders in the facility and the community.

Public Health Nursing ***1975 – 1981***
School Nurse: Town of Wilbraham
Camp Nurse: Wilder Day Camp

Responsible for the planning and development of health services, maintenance of health records, complying with Department of Public Health Records, staff education and first aid.

Regional Director *1971 – 1973*
Massachusetts Association for Mental Health

Agency liaison to three local chapters of Massachusetts Association of Mental Health; organized and implemented fund raising campaign in four county area; program planning and development; agency policy and by-law development, development and management of the budget, volunteer services, legislative advocacy and community relations.

Staff Nurse – Obstetrics *1965 – 1971*
Wesson Women's Hospital, Springfield, MA

Head Nurse, Staff Nurse *1963 – 1965*
Woodside Psychiatric Hospital, Youngstown, OH

Consultations:

Expert Witness:
See page 2 under Litigation

Management Consultations:
American Training, Inc., Lawrence, Massachusetts
Vanguard Associates, Chicopee, Massachusetts
New Bedford Harbor Associates, New Bedford, Massachusetts
Franklin/Hampshire Area Office, Massachusetts Department of Mental Retardation
Riverbrook Residences, Stockbridge, Massachusetts
Mental Health Association, Springfield, Massachusetts
Morgan Memorial Goodwill Industries, Boston Massachusetts
Viability, Northampton, Massachusetts

Grants:

Arc Mass Systems Change Grant
"The Bridge Project", Pioneer Valley United Way, seven years of funding.
"Supporting Individuals with Cognitive Limitations during Hospitalization", the Massachusetts Developmental Disabilities Council.
"Community Integration Project", the Community Foundation.
Purchase of wheelchair van, the Beveridge Foundation.
"Berkshire Community Integration Project, the Berkshire Taconic Community Foundation.
"Developing Supports for Kinship and Single Parent Families in the Berkshires", the Berkshire Life Foundation.

Leadership Roles:

President, Human Service Forum, 2014-2016
President, Western Massachusetts Service Providers, 2008-2010
Massachusetts ICF/MR Providers Organization, President, 3 years

Mental Health Association of Greater Springfield, President, 3 years
Springfield Area Board, Department of Mental Health, President, 2 years
UMass/Department of Mental Retardation Committee on Screening Guidelines for Health Care for people with developmental disabilities, 2001.
Editorial Board, *The International Journal for Nursing in Intellectual and Developmental Disabilities*, current.
Member, AAMR Professional Delegation to China, 2001.
Massachusetts Department of Mental Retardation Health Care Initiative Project, DMR Strategic Plan, 2003
Chair, Complex Medical Needs Task Force, 1998-2006.
Chair, Association of Developmental Disabilities Providers (ADDP)/Department of Mental Retardation (DMR) Health Care Partnership Committee, 2000-2005.
American Network of Community Options and Resources, Federal Taxation Legislation Committee, 1998-2001.
Baystate Medical Center Visiting Nurse and Hospice Association Ethics Committee, 1994-2002.
ADDP/DMR Shared Living Task Force, 1999-2001.

Presentations:

Shriver Center for Developmental Disabilities' Evaluation and Research state conference on Prevention, Risk and Safety, October, 2012
Massachusetts Association of Developmental Disabilities Providers: End of Life presentation, November 2007
Developmental Disabilities Nurses' Association 11th Annual Conference, March 2006.
Eleventh International Nursing Research Congress, Hawaii USA, 2005
Massachusetts Annual Shared Living Conference, 2001-2004, 2008.
National Association of Adult Foster Care Providers, 2001**.**
Massachusetts Department of Mental Retardation Human Rights Conference.
Massachusetts Association of Developmental Disabilities Providers Annual Conference.
Massachusetts Association of Developmental Disability Providers Conference on Shared Living.
Developmental Disabilities Nurses' Association 9th Annual National Conference.
The International Association for the Scientific Study of Intellectual Disabilities, XI International Congress, Seattle, WA, USA; XII International Congress, Montpellier, France; XIII International Conference, Cape Town, South Africa
Massachusetts Department of Mental Retardation: Statewide Quality Enhancement Surveyors Conference.
"Supporting People with Developmental Disabilities during Hospitalization" to over 500 professionals at various seminars.
Western New England College School of Law, Disability Law Clinic.
American International College, School of Nursing.
IASSID 2016 International Congress; Melbourne Australia; August 2016
IASSID USA Conference; Chicago Illinois; July 2016

Community Agencies:

Hawthorn Elder Services, Board Member, 2007-2011
Minnechaug Land Trust, 2008-current
Massachusetts Association for Mental Health, Executive Committee, Officer
Child and Family Services, Springfield, Board Member
Department of Social Services Advisory Board, Charter Member
Community Care Center, Springfield, Corporator, Officer
Springfield Comprehensive Mental Health Center, Board Member
Human Service Forum Long-Range Planning Committee
DMR Psychotropic Drug Review Committee
Mental Health Association, President, Board Member

Publications:

“Supporting Individuals with Cognitive Disabilities during Hospitalizations: A Training Manual”.
“Services for People with Developmental Disabilities in China: An American Perspective” *International Journal of Nursing in Intellectual and Developmental Disabilities, Spring 2004 Issue;* www.ddna.org.

Academic Honors:

Sigma Theta Tau International Nursing Honor Society
Alpha Chi Honor Society
Highest Achievement in Psychiatric Nursing

Education:

BS in Nursing, American International College, Magna cum Laude
Trumbull Memorial Hospital School of Nursing, Highest Achievement in Psychiatric Nursing
MS Program, School of Public Health, University of Massachusetts, Amherst, 9 credits
RN licensed in Massachusetts, Inactive in Ohio

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 BARBARA PILARCIK
Attachment B

	Document	**Bates No.**
1.	Kathryn Dupree's Q1 2016 QSR	DefE-00000601-672
2.	Active Treatment Protocol for Class Member used in *Rolland v. Patrick* (DRAFT dated January 17, 2008)	PL00000001-14
3.	Follow Up Review for Class Member used in *Rolland v. Patrick* (Final dated November 16, 2011)	PL00000042-59
4.	Reviewer's and Quality Review Judges Guide used in *Rolland v. Patrick*, dated January 21, 2008	PL00000015-41
5.	Kathryn Dupree's 2015 Annual Compliance Report	DefE-00000677-716
6.	QSR Matrix	PL00000060-136
7.	Letter from Lynn Rucker to Judge Neiman in *Rolland v. Patrick*, dated December 7, 2007	PL000000767-768
8.	Active Treatment Protocol for Class Member used in *Rolland v. Patrick* (Final DRAFT dated Dec. 7, 2007)	PL000000769-840
9.	*Olmstead v. L.C.*, 527 U.S. 581,583 (1999)	
10.	40 T.A.C., Part 1, Chapter 19, subchapter BB: NF responsibilities related to PASRR	PL00000251-263
11.	Attachment G – PASSR Requirements and Enhanced Community Coordination	PL00000236-250
12.	LIDDA PASRR Reporting Manual, revised October 2015	PL00000200-214
13.	2016 PASRR QSR Compliance Status Interim Report	DefE-00096540-96568
14.	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	US00253559-00252568
15.	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
16.	42 C.F.R. § 483.440, Condition of participation: Active treatment services.	US00253366-253372
17.	TEX. HEALTH AND HUMAN SERVS. COMM'N, *PASRR Webinar: Specialized Services for Nursing Facility*	US00253271-00253365

	Residents with IDD, April 25, 2017	
18.	40 T.A.C., Part 1, Ch. 17, Subch. A-E, Preadmission Screening and Resident Review (PASRR)	US00253388-253401
19.	40 T.A.C., Part 1, Ch. 19. Subch. BB: NF responsibilities related to PASRR	US00253402-253410
20.	TEX. HEALTH AND HUMAN SERVS. COMM'N, (formerly, Texas Department of Aging and Disability Services), *Explanation of IDD Services and Supports*	US00253411-253423
21.	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	US00253424-253429
22.	Active Treatment Standards, Center for Medicaid and Medicare Services *available at* https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R135SOMA.pdf	
23.	Reading the Stars: Nursing Home Quality Star Ratings, Nationally and by State – Kaiser Family Foundation, 2015 *available at* http://files.kff.org/attachment/issue-brief-reading-the-stars-nursing-home-quality-star-ratings-nationally-and-by-state	
24.	National Core Indicators National Core Indicators Report At-A-Glance; Adult Consumer Survey 2015-2016. *available at* http://www.nci.org	
25.	Information Letter No. 15-33, Prior Authorization for Preadmission Screening and 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	US00253430-253432
26.	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

27.	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
28.	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
29.	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
30.	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
31.	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
32.	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
33.	PASRR Review Process and Service Coordination Participant Guide, July 2016	DefE-00055401-55459
34.	Nursing Facility records request letter	US00253268-253270
35.	LIDDA records request letter	US00253265-253267
36.	Spreadsheet: NF Transition Snapshot	DefE-01958693

37.	Nursing facility records for SBa	US00106694-107634 US00177998-178142
38.	LIDDA records for SBa	US00112174-112209 US00162348-162507 US00181232-182409
39.	Nursing facility records for CB	US00107658-108033 US00175395-175527
40.	LIDDA records for CB	US00166171-166480 US00178191-178278
41.	Nursing facility records for SBo	US00085792-87473
42.	LIDDA records for SBo	US00151927-152231 US00172454-172479
43.	Nursing facility records for LB	US00159381-159913 US00172370-172445 US00181263-181277 US00182552-182575
44.	LIDDA records for LB	US00110046-110186 US00169888-169993 US00181815-181829
45.	LIDDA records for VC	US00112338-112713 US00125621-125999 US00172592-172611
46.	Nursing facility records for VC	US00172080-172182
47.	Nursing facility records for WD	US00110267-110800 US00177268-177344
48.	LIDDA records for WD	US00136884-137483 US00172557-172591
49.	Nursing facility records for SE	US00084492-84623
50.	LIDDA records for SE	US00103497-103895 US00178452-178463
51.	Nursing facility records for BF	US00083587-84203 US00173485-173791
52.	LIDDA records for BF	US00166861-167031 US00175234-175237 US00177345-177358
53.	Nursing facility records for SH	US00097242-99789 US00171400-171490
54.	LIDDA records for SH	US00111315-111360 US00169994-170049 US00182215-182233
55.	LIDDA records for AH	US00112294-112337 US00151094-151152
56.	Nursing facility records for AH	US00113282-114166

		US00128012-128886 US00175238-175268 US00182410-182420
57.	LIDDA records for DH	US00111993-112046 US00114429-114444 US00164105-164216 US00178545-178562 US00182314-182329
58.	Nursing facility records for DH	US00165383-165776 US00193082-193298
59.	Nursing facility records for BH	US00122230-123171 US00179840-179964 US00192892-193016
60.	LIDDA records for BH	US00167032-167239 US00175269-175288
61.	Nursing facility records for DK	US00140627-141760 US00161888-162347 US00182482-182486 US00193299-193538
62.	LIDDA records for DK	US00151678-151926 US00172547-172556
63.	LIDDA records for JM	US00096588-97069 US00103896-104377 US00129545-130026 US00168774-168826
64.	Nursing facility records for JM	US00104378-105527 US00130027-131176 US00172743-172847
65.	LIDDA records for CN	US00100831-101454 US00105528-105577 US00131177-131850 US00168839-168889
66.	Nursing facility records for CN	US00105578-106693 US00170973-171052
67.	Nursing facility records for DPar	US00103142-103496 US00170538-170614 US00171130-171225 US00172197-172369 US00182481
68.	LIDDA records for DPar	US00108034-108331 US00178365-178451
69.	LIDDA records for DPay	US00121153-121327 US00151215-151289 US00170344-170378 US00182330-182345

70.	Nursing facility records for DPay	US00137484-140626 US00170378-170530 US00182487-182500
71.	LIDDA records for SS	US00115409-115835 US00121328-121370 US00132529-132955 US00168692-168722
72.	Nursing facility records for SS	US00135765-136177 US00149734-150146 US00170876-170944 US00171053-171129
73.	LIDDA records for AS	US00108332-108542 US00178279-178364
74.	Nursing facility records for AS	US00164903-165382 US00181830-182214
75.	Nursing facility records for TS	US00115893-117421 US00133428-134956 US00172848-172942
76.	LIDDA records for TS	US00132956-133427 US00136178-136649 US00150147-150618 US00168723-168765
77.	Review of Individuals in Nursing Facilities Questions & Considerations	US0258739-258741