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# Strategies and Challenges in Promoting Transitions from Nursing Facilities to the Community for Individuals with Disabilities: **A Pilot Study of the Implementation of Rider 37 in Texas**

Jay Klein  
Pam Walker  
Celia Feinstein  
Paula Margeson  
Darrell Lynn Jones

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**Community Living Exchange**  
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for Individuals with Disabilities: **A Pilot Study of the  
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Institute on Disability, University of New Hampshire

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ILRU Program  
2323 S. Shepherd, Suite 1000  
Houston, TX 77019  
713/520-0232 (Voice)  
713/520-5785 (Fax)  
713/520-5136 (TTY)  
*http://www.ilru.org*

**Community Living Exchange Collaborative at ILRU Publication Team:**  
Richard Petty, Darrell Lynn Jones, Sharon Finney, Cathy Zimmermann

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ILRU is a program of TIRR, a nationally recognized, freestanding rehabilitation facility for persons with physical disabilities. TIRR is a part of TIRR Systems, which is a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

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## Executive Summary

The 1999 Supreme Court decision in Olmstead vs. L.C. requires States to provide services to qualified individuals with disabilities in the most integrated setting. This ruling was a major catalyst for President Bush's 2001 New Freedom Initiative that directs federal agencies to remove barriers to community living. Based on the Olmstead Decision and input by advocates and other stakeholders, the Texas Legislature (2001-2005) attached a Rider to the Appropriations Bill that states: "It is the intent of the legislature that as clients relocate from nursing facilities to community care services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services." As of August 30, 2003, over 2,000 individuals used this Rider (originally 37 and now 28) to move to the community.

The Community Living Exchange Collaborative at ILRU, the National Resource Center on Supported Living and Choice, and the Center for Housing and New Community Economics, conducted a small pilot qualitative study of the implementation of Rider 37 from June 1, 2003 through September 30, 2003. The objective of the pilot study was to investigate the implementation of Rider 37, with a focus on the transition process as well as quality of life outcomes in the community. Six people who moved out of nursing facilities under the Texas initiative participated in interviews. Individuals who assisted each of the six people in the transition, as well as other key stakeholders, also participated in interviews.

The six study participants who moved out of nursing homes represent a range of ages and racial/ethnic groups and lived in six different regions of Texas. Four currently live in their own homes or apartments, one lives in a family member's home, and one resides in an assisted living facility. The time spent in nursing facilities ranged from 3 months to 24 months, with an average of 11 months. Three people said that their preference would have been to move back to their own homes. At the same time, there was unanimous agreement that the places they are living now are "much better" than the nursing facility. Some of the most positive aspects about their transition include more independence and control of their lives, more contact with family members and friends, and increased opportunity to participate in community life.

A number of factors were critical in the implementation of Rider 37 including the legislation that made it possible; the Promoting Independence plan; the commitment from state human service agencies; the opportunity to obtain community services funding without having to be placed on lengthy waiting lists, and funding made available by the state for housing supplements, relocation efforts, and transition costs. The interviews and focus group identified a number of factors that constituted challenges or barriers to implementing Rider 37 as well as essential actions to pursue in the future.

There was also unanimous agreement among those who participated in interviews about the success of Rider 37—primarily, that it succeeded in offering more independence, choice, and control to 2,022 individuals who lived in nursing facilities. Participants assumed that Rider 37 resulted in a considerable cost savings. They recognized Rider 37 as promoting new and positive experiences of collaboration that resulted in significant learning about strategies and barriers in nursing facility transition and a deeper understanding about the types and amount of work required for people to transition.

## Introduction

In June 1999, the Supreme Court of the United States issued a decision in the Olmstead vs. L.C. and E.W. case (Olmstead v. L.C. 119 S. Ct. 2176, 1999). This decision upheld Title II of the Americans with Disabilities Act, which requires a “public entity to administer programs in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (Americans with Disabilities Act, PL 101-336). Since the Olmstead ruling, the states have engaged, in different ways, in efforts to respond (Fox-Grage, Folkemer, & Lewis, 2003; National Association of Protection and Advocacy Systems, Inc., 2001, 2002; National Council on Disability, 2003).

The federal government has supported these efforts with Congressional appropriations for the “Real Choice Systems Change Grants for Community Living.” The Centers for Medicare and Medicaid Services (CMS) has provided \$125 million in 2001 and 2002 to 48 states, the District of Columbia, and two territories to design and implement enduring improvements in community long-term support programs (<http://cms.hhs.gov/systemschange>). The Real Choice Systems Change Grants are a major component of President Bush’s New Freedom Initiative.

In FY 2003, Congress appropriated an additional 40 million dollars for a new round of Real Choice Systems Change Grants for Community Living. A portion of this new round of funding specifically focuses on funding Money Follows the Person Rebalancing Initiatives.

Several years prior to the creation of this federal initiative, the Texas Health and Human Services Commission (HHSC), in response to the Olmstead decision, and input by advocates and other stakeholders, created Promoting Independence. As one of the outcomes of Promoting Independence, in 2001, the Texas Legislature passed into law a provision attached to the Appropriations Bill under the Texas Department of Human Services (DHS) known as Rider 37. This “Money Follows the Person” initiative has been recognized as a national “promising practice” (National Association of Protection and Advocacy Systems, Inc., 2002). The rider states: “Promoting Independence: It is the intent of the legislature that as clients relocate from nursing facilities to community services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services.”

The Community Living Exchange Collaborative at ILRU, HHSC and DHS were interested in examining the impact of Rider 37, beginning with a small pilot study. The objective of the pilot study was to investigate the implementation of Rider 37, with a focus on the transition process as well as quality of life outcomes in the community. This pilot study is based upon the perspectives of people with disabilities who moved out of nursing facilities and family members or others who assisted in the transition process, as well as the perspectives of a variety of stakeholders, including Relocation Specialist administrators, DHS administrators, advocates, and others. This is a report on the findings of the pilot study.

## **Methodology**

This study was designed as a small-scale, pilot qualitative study of the implementation of Rider 37 (Lincoln & Guba, 1985; Patton, 1980; Taylor & Bogdan, 1998). Six people who moved out of nursing facilities participated in interviews. The individuals were intentionally chosen to represent six different regions of the state (i.e., so as to include regions with and without relocation specialists, as well as more urban versus rural regions), and to represent different age groups (e.g., three people 73 years old or older and three people who are 55 years or younger). The study team randomly chose six individuals from lists of Rider 37 participants, broken down by age within different regions. Individuals who had assisted each of the six people in the transition (e.g., family members, relocation specialists, and others) also participated in interviews. Other key stakeholders who participated in interviews included:

- three relocation specialist administrators,
- one HHSC administrator,
- one DHS administrator,
- a legislative aide,
- a staff member of Every Child, Inc. (a non-profit agency focused on finding families for all children), and
- six advocates in Texas (recommended by members of the planning team) who have worked in various capacities to promote community living for children and adults.

Interviewers talked with participants both in person and by telephone, using two interview guides one for Rider 37 participants and their assistants, and one for other stakeholders. The guides consisted of both closed-ended and open-ended questions. Five of the six advocates participated in a focus group; the sixth was interviewed by telephone; these interviews were unstructured and were directed by one of the interview guides. Data from the interviews and focus group were analyzed to identify key themes and issues.

### **Background to Rider 37**

In 1999, the Promoting Independence Advisory Board was formed, as directed by then Governor George Bush (SB 367 Task Force, 2002). This Advisory Board includes representatives of health and human service agencies, related work groups, consumer and family advocacy groups, and providers of services. The Commissioner of the HHSC appoints advisory board members. During FY '99 and FY'00, the Promoting Independence Advisory Board met and assisted the HHSC in the development of the Promoting Independence Plan. During the 77th Session of the Texas Legislature, SB367 was passed. This bill renamed the Promoting Independence Advisory Board as the SB 367 Interagency Task Force on Appropriate Care Settings for Persons with Disabilities. Many members of the original Promoting Independence Advisory Board continued in their appointments (Texas Health and Human Services Commission, 2002).



During the 77th Session, among other things, Rider 37 was passed for the FY 02 –03 biennium. The Rider went into effect in September 2001. Over the next several months the HHSC, DHS, and the Advisory Board developed an implementation plan.

Part of this implementation plan was a pilot project involving the competitive procurement of organizations to provide Community Awareness and Relocation Services (CARS). Based on a request-for-proposals (RFP) process, these contracts were awarded to three sites:

- A collaborative between the Austin Resource Center on Independent Living (ARCIL), Houston Center for Independent Living (HCIL), and Crockett Resource Center for Independent Living (CRCIL);
- Accessible Communities, Inc./Coastal Bend Independent Living Center in Corpus Christi (CBCIL); and
- A collaborative between Combridge, Inc and the Heart of Central Texas Independent Living Center (HOCTIL). The contracts for these centers were for one year, beginning May 31, 2002 to May 30, 2003; later they were extended through November 30, 2003.

The implementation plan also referenced the availability of 35 set-aside Section 8 housing vouchers for individuals under age 62 moving from nursing facilities to the community. These vouchers came through the Texas Department of Housing and Community Affairs (TDHCA), which received an allocation from the department of Housing and Urban Development (HUD) through a demonstration project called Project Access. Thus, some Rider 37 participants did not have to go through the typical waiting list process for funds to supplement their housing costs. In addition, a transition grant of up to \$2,500 was available from DHS to assist many of the individuals who moved (however, some individuals were not eligible for this grant).

In order to be eligible for transition to the community through Rider 37, a person must be eligible for one of the DHS Medicaid Community Care Programs and must be receiving Medicaid support for nursing facility services. Because the money follows individuals from the nursing facility into the community, they do not have to be placed on waiting lists for DHS Medicaid community care programs. Accompanying Rider 37 was Rider 7b, which specified that the cost for community services could not exceed either the average Medicaid Nursing Facility rate or the individual's nursing facility rate, whichever was greater.

As of August 31, 2003, over 2,000 people utilized the Rider 37 funding mechanism to move out of nursing facilities. The following section provides some demographics related to Rider 37 participants. Following the demographics is an introduction to the six Rider 37 individuals who participated in interviews, as well as individual profiles of each person. Next is a section identifying themes and issues based on interviews with the participants, people who most closely assisted with the transition, and other stakeholders. The final two sections discuss further research issues and provide concluding comments.

## Demographics Across All Rider 37 Participants

Between September 1, 2001 and August 31, 2003, over 2,000 individuals moved out of nursing facilities through Rider 37. As depicted in the following Texas regional map, the greatest percentages of people moved out in Regions 3 – Metroplex (25%), 4 – Upper East Texas (14.6%), 7 – Central Texas (12.8%), and 11 – Lower South Texas (11%); the lowest percentages were in Regions 10 – Upper Rio Grande (2.2 %), 6 – Gulf Coast (2.5%), 9 – West Texas (3.5%), and 1 – High Plains (3.9%).

### Texas Department of Human Services Regional Boundaries



In general, this seems to correlate with higher percentages in urban areas of greatest population, and/or areas that received CARS contracts. (However, it is interesting to note that in the Dallas area, which received no CARS contract, the greatest numbers of people were assisted to transition out of nursing facilities, while Houston, which received a CARS contract, was among the lowest numerically)

The following tables show the demographic breakdown by age, race/ethnicity and community setting where individuals re-located:

<b>Age Range</b>	<b>Percentage</b>
0-21	.3%
22-44	6%
45-64	26%
65-80	31%
80+	34%

<b>Race/Ethnicity</b>	<b>Percentage</b>
White	69%
Hispanic	17%
Black	10%
Asian/Pacific Islander, American Indian, and Other racial/ethnic groups	2%

(The 2000 state census for the general population of Texas gives 53.1% White, 32% Hispanic, 11.6% Black, and 3.3% Asian/Pacific Islander/American Indian.)

<b>Setting</b>	<b>Percentage</b>
Own home	26%
Assisted Living (classified as "alternative living/residential care")	32%
Family members home	37%
"With other waiver participants"	2.5%
Adult foster care	1%
Unknown	1%

## Rider 37 Case Studies

### Introduction

The six people who participated in interviews range in age from 26 to 85. They live in six different regions of the state (one each from Regions 3, 4, 7, 8, 11, and 6). Three of the study participants are Caucasian, two are African American, and one is Latino/Hispanic. Four are currently living in their own homes or apartments, one is living in a family member's home, and one resides in an assisted living facility.

Two of the individuals moved to nursing facilities following surgery, two needed medical care, one transferred into a nursing facility when the insurance benefits which covered the cost of a rehabilitation center were exhausted, and one was admitted to a nursing facility when family members could no longer provide care. The time spent in the nursing facilities ranged from 3 months to 24 months, with an average of 11 months.

These six individuals learned about the opportunity to leave the nursing facility from a variety of sources. One heard from a DHS social worker, two from family members, two from nursing facility social workers, and one in an e-mail from a relocation specialist. Three of the individuals were aware of the existence of a formal "transition plan" related to their move out of the nursing facility; and three were not aware of any such plan. From the time they began working toward their move, it took an average of approximately 5 months to leave the nursing facility.

All six people reported having received assistance in their move from family members. Other sources of support included relocation specialists, DHS staff, friends, and the social worker at the nursing facility. However overall, the six individuals considered family members the most helpful. Most people reported that nursing facility staff was not helpful or of little assistance and sometimes, in fact, they considered staff to be a barrier in the process. Other barriers or challenges included the amount of paperwork, the length of time spent waiting for approval, and family concern or opposition.

The support the six individuals receive comes from a variety of sources. For instance, three receive personal assistance services; of these, the greatest number of hours of weekly assistance is 51. (It should be noted that the person who receives this amount of assistance considers it to be insufficient.) One person who receives personal assistance services uses his sister as the paid provider; two other individuals live with family members or friends who provide assistance, but are not paid to do so. Some of the individuals receive paid assistance with medication administration and home health care. Five of the six obtained medical equipment, primarily through the Community-Based Alternatives (CBA) waiver (a waiver that funds services to people who have disabilities); one obtained a communication device through the Texas Rehabilitation Commission (TRC).

Three people said that their preference would have been to move back to their own homes. One of these people is living with her parents, one person is living in an assisted living facility, and the other person is living in an apartment in a public housing complex. Also, three mentioned difficulties with lack of transportation in the community. At the same time, there was unanimous agreement that the places they are living now are "much better" than the nursing facility. Some of the most positive aspects about their transition include more independence and control of their

lives, more contact with family members and friends, and increased opportunity to participate in community life. Profiles of each of the six individuals are presented below. All of the names are pseudonyms.

## Profiles

**Liz**, Since she was a teenager, Liz, who is now 38, has been an independent, determined person. She moved out of her parents' home at 18, and worked toward ownership of her own car, her own home, and then her own business. After a series of strokes, however, she moved into a rehabilitation center. When her insurance benefits expired, she was transferred to a nursing facility. From the perspective of Liz and her father, she was not receiving adequate care in the nursing facility (e.g., improper or insufficient cleaning of her feeding tube, lack of rehabilitative therapy). Liz's father was determined to get her out, with or without assistance from the system. Not knowing where to go for help, he contacted the Office on Aging, who referred him to the regional Relocation Specialist. Liz and her family enlisted the assistance of a Relocation Specialist, who helped initiate the process of transitioning from the nursing facility. A case manager from DHS assisted them in arranging for needed services and in-home modifications.

In November 2002, after 3 months in the nursing facility, Liz moved into her parents' home. Liz's first choice would have been to live in her own home, but she and her parents did not believe that she would receive the necessary support to ensure her safety and comfort. At the time, they felt the only possibility was for her to live with family. She receives medical care through the CBA waiver, visits from a home health care worker every 2 months, some in-home accommodations (e.g., wider doorways and grab bars to make the bathroom accessible), and a supplemental nutrient. They are still waiting for one more grab bar to be installed in the bathroom. Liz's parents provide her with assistance (e.g., in meal preparation, some transfers, transportation). While Liz's father feels that the supports are adequate, he says that Liz's mother feels that Liz should have some personal assistance in addition to what her parents can provide. Liz's father reports that she was denied housing assistance that would have enabled her to live in her own home (e.g., either a Section 8 voucher or public housing), and that she was also denied assistance from TRC.

From the perspective of Liz and her father, one of the biggest frustrations was the length of time it took to begin receiving SSI payments. They reported that it was this delay that caused Liz to lose her business, her car, and her home. Liz's father reflected, "Why put people through the process of losing everything, so when they get out, they don't have anything to go back to?"

Despite the frustrations, Liz is very happy to be out of the nursing facility. Surrounded by family and the animals she loves, she says she is not as depressed as she was in the nursing facility; she has much more opportunity to increase and enhance her mobility, and she feels a sense of freedom.

**Martha**, who is 85 years old, lived in her own home with her husband until she fell and hit her head, which resulted in the development of a blood clot. Following surgery, she was placed in a nursing facility, where she spent the next 19 months. During this time, her husband passed away. The DHS case manager informed her granddaughter that there might be an opportunity for Martha to leave the nursing facility. Martha credits her granddaughter with doing most of the work to facilitate her move. She now lives in her own apartment, within a HUD-funded senior housing complex. While she feels this is a much better place to live than the nursing facility, she would have preferred to move back to her own home. However, according to Martha, her family members and the

DHS worker were not supportive of this, as the house was not accessible and there was no emergency response system. Her family and the DHS worker recommended that she move to an assisted living facility, but Martha was not interested in that option.

Martha receives 12 hours of personal assistance services per week, and she obtained an electric wheelchair through the CBA waiver. The most difficult aspects of the transition for her were the amount of paperwork and the lengthy wait for CBA approval. She is frustrated by her immobility due to lack of a vehicle or other means of transportation. At the same time, Martha is happy to have her independence back, to be in her own place with her own things, and to be back in the community near her family and members of her church.

**Joe**, who is also 85 years old, ended up in a nursing facility because of malnutrition due to his poor diet and excessive drinking. He remained there for 11 months. Joe initiated his own move from the nursing facility, based on discussion with the nursing facility social worker, who then referred him to a Relocation Specialist. A number of people assisted with Joe's transition from the nursing facility, including family members, friends, long-term care staff, and the Relocation Specialist, but the key person was a friend who lives with Joe and provides him with assistance. Eventually, Joe moved back into his own apartment. Before Joe moved into the nursing facility, his roommate was paid to provide him with personal assistance. Joe reported that when he moved back home, he was denied funding for personal assistance services based on his roommate's financial situation and her availability to assist him.

As Joe prepared to leave the nursing facility, there were many challenges. One was finding someone to help move Joe's belongings from storage and the nursing facility into his apartment. Another was that, because of his history, his family members were not entirely supportive of his move. Joe, however, is very positive about the move, and feels as though the move out of the nursing facility gave him his life back. He states, "I didn't have a life in the nursing home... Now, I can do what I want to do, go where I wish, and eat what I want to eat."

**Carlos**, a 26-year old father of three, spent 9 months in a nursing facility in San Antonio following the amputation of both legs as a result of diabetes. A social worker in the nursing facility contacted COIL (the Center on Independent Living) on behalf of Carlos. Staff at COIL was instrumental in helping Carlos with his move. Others who assisted include his family, the social worker, his DHS case manager, and Advocacy, Inc., in Austin.

In planning his transition from the nursing facility, Carlos's two main priorities were to have his own home and to live near his children and his large, extended family. He looked at four possible places to live; ultimately, he moved into his first choice. It is a completely accessible home, within a small complex of accessible homes built with Community Development funds. Because Carlos owed back child support payments, he was not eligible for a transition grant from DHS. However, COIL was able to obtain donations to cover expenses such as furniture, his first month's rent and utilities, an initial supply of food, and other immediate necessities for his move. COIL also loaned him various equipment (e.g., accessible bath benches, chairs, reacher) until he was able to obtain his own through the CBA waiver. Through the waiver, Carlos receives 23 hours of personal assistance per week. His sister is the paid provider. In addition, he has

monthly visits to a doctor, and has weekly visits from a home health care provider. He is currently waiting for prostheses. Once he adjusts to these, he is interested in working toward his GED and obtaining employment.

For Carlos, perhaps the most important aspect of his move from the nursing facility into his own home is his improved relationship with his children. He explained, “They were afraid of visiting in the nursing home. Now they can come here, stay overnight, ride their bikes.” Although other family members visited him frequently in the nursing facility, it is very important to Carlos to be living back in the community. Finally, the move into his own home has given Carlos a sense of independence, privacy, and freedom.

**Lynn**, who is 27 years old, had been living with family members prior to entering the nursing facility. She was placed in a nursing facility for a variety of reasons, including complications from diabetes as well as a psychotic episode, and spent 4 months there. Her sister, who is a discharge planner at a long-term care facility, was the primary person who helped arrange her transition from the nursing facility to an assisted living facility; the administrator of the assisted living facility was also helpful. Lynn said that one of the barriers she faced during her transition was that the staff at the nursing facility insisted that she wasn’t capable of living elsewhere. Overall, one of the most challenging aspects of her life now is adjusting to the rules and regulations of an assisted living facility. At the same time, positive aspects of her life include more control and independence than in the nursing facility. Lynn hopes that someday in the future she will be able to move into her own apartment.

**Dave**, who is 26 years old, entered a nursing facility when the family members with whom he was living could no longer provide the assistance he needed. He spent 2 years in the nursing facility. While in this facility, Dave maintained e-mail contact with a broad network of friends and acquaintances. One of these people, a former high school teacher of Dave’s, heard about Rider 37 and contacted the Relocation Specialist on behalf of Dave. The Relocation Specialist then contacted Dave and they began planning for his transition to the community. In addition to assistance from the Relocation Specialist, others who helped with the transition include family members, friends, and staff of the TRC (Texas Rehabilitation Commission).

After 7 months of work on the transition, Dave moved from the nursing facility into his own apartment. He receives support from a variety of sources. His family has helped with furniture, clothing, and home modifications; through TRC, he obtained a communication device; and through the CBA waiver he obtained a bath lift and receives 51 hours of personal assistance services per week. Dave states that this level of personal assistance is insufficient, as it does not allow adequate time for assistance with participation in community life, such as church attendance.

The major challenges related to the transition were the amount of paperwork as well as the length of time required. A significant challenge in the community is the lack of reliable transportation. According to Dave, positive aspects of life in the community include “being on my own,” having the communication device, and being “more in touch with the community.”

## Themes and Issues Regarding Implementation of Rider 37

This section is based on data from all of the interviews (including Rider 37 participants, those who assisted them, and stakeholders) and from the focus group. It discusses themes and issues related to: successes of Rider 37; what has facilitated implementation of Rider 37; challenges and barriers in implementing Rider 37; variability of success with implementation within the state; lessons about what it takes to make this happen; and future directions.

### Successes in Implementing Rider 37

There was unanimous agreement among interview participants and the study team that Rider 37 and its implementation were successful for a number of reasons. Five of the major reasons include:

1. **Movement of 2,022 people.** The greatest success is the fact that 2,022 people of all ages, including some with significant support needs, moved out of nursing facilities from September 1, 2001 through August 31, 2003. As a result, these individuals have much greater opportunities for choice, independence, and community life.
2. **Increased awareness.** The implementation of Rider 37 has raised awareness within the legislature and among people with disabilities and their families about the possibilities of community living.
3. **Learning experience.** The collective experience of implementing the transitions from nursing facilities—by people with disabilities, family members, advocates, DHS staff, relocation specialists, and others—promoted the realization that “it really can be done,” and generated a deeper understanding about the types and amount of work required to make it happen.
4. **Increased collaboration.** Efforts to implement Rider 37 promoted new or increased collaboration among various stakeholders, who felt that the collaboration, alone, represented one of the major successes of Rider 37.
5. **Cost savings.** Participants in the study assumed that Rider 37 resulted in a considerable cost savings. DHS has reported that in State Fiscal Year 2002, the Community Based Alternative (CBA) Waiver served an average of 443 people per month who entered the program via Rider 37. During this time, Texas spent an average of \$1188.70 per month for these individuals, compared to an average monthly nursing facility cost per person of \$2373.66. In Fiscal Year 2003, Texas served an average of 1513 CBA individuals per month who entered the program using Rider 37 at an average monthly cost of \$1256.721, compared to a monthly average Nursing Facility cost of \$2375.49.

Based upon the change in the Medicaid Nursing Facility caseload trend before, versus after the implementation of Rider 37, it appears that a significant number of people who used Rider 37 to leave the Nursing Facility would have left regardless of whether Rider 37 had been in force. Therefore, the Texas Department of Human Services (DHS) cannot accurately determine the amount of the budget impact of Rider 37. However, given the 2:1 differential between the cost of Nursing Facility care vs. Community Based Alternative Waiver, DHS is fairly confident that Rider 37 was cost neutral during the ‘02-‘03 Texas state budget biennium. Further study will need to be conducted to establish the actual economic impact.



## What Facilitated Rider 37 Implementation?

A number of factors were critical in the implementation of Rider 37.

- 1. Legislation and a plan.** People felt it was important that there was a plan with legislation behind it, and that the Promoting Independence /SB 367 Task Force met regularly to give input on the plan and its implementation.
- 2. DHS commitment.** It was significant that DHS had a strong commitment to timely and successful implementation of Rider 37, and, as one stakeholder put it, “once the legislation was passed, they hit the ground running.” In addition, stakeholders who were not associated with DHS appreciated the highly positive collaboration they had with DHS in implementing the transitions. For example, in San Antonio, a strong collaborative team that included DHS representatives as well as providers and advocates was created. This group worked together to strategize and problem-solve issues related to both individual transitions as well as systems challenges.
- 3. Funding to support relocation efforts.** The consensus was that having available funding earmarked to support relocation greatly enhanced these efforts. The primary source of funds was the CARS contracts. In a separate but related initiative, the Texas Community Integration Collaborative (an initiative of Advocacy, Inc., the Texas Council for DD, and the Center for Excellence at the University of Texas) supported relocation efforts in the San Antonio area.  
  
These resources enhanced the publicity about Rider 37. Overall, Rider 37 was publicized in many different ways (e.g., web sites, mailings, face-to-face contact), by a wide variety of groups including DHS, the CARS offices, Independent Living Centers (ILCs), and a range of other agencies and advocacy groups. Many of those who participated in interviews expressed that the most important and effective means of raising awareness was through face-to-face contact within nursing facilities. The ability of ILCs and others to engage in this personal contact was greatly enhanced by the funded projects. The funding also assisted with the sometimes overwhelming amount of “hands-and-feet” work needed to accomplish smooth transitions from nursing facilities, and assisted with community networking, as well.  
  
Staff at the independent living centers that received funding to support relocation have, prior to Rider 37, worked to get people out of nursing facilities, and will continue these efforts, even as funding ends. However, it is the general impression among many stakeholders that the funding greatly enhanced these efforts, enabling them to reach many more people overall, and enabling them to include people with greater and more complex support needs.
- 4. Transition grants and Project Access Section 8 vouchers.** Both the transition grants from DHS and Project Access housing vouchers from DHCA facilitated the implementation of Rider 37. The transition grants provided critical startup funds for people who moved into their own homes or apartments, many of whom had little clothing, furniture, or other personal property.
- 5. Money follows the person.** Rider 37 enables money to follow people as they move from nursing facilities to the community; thus, they are able to obtain Medicaid community care program funding without having to be placed on lengthy waiting lists.

## Challenges and Barriers in Implementing Rider 37

The interviews and focus group identified a number of factors that constituted challenges or barriers to implementing Rider 37.

1. **Individuals with no family or community networks.** Stakeholders agreed that it was more difficult to assist people who had no family and/or contacts in the community to transition out of nursing facilities. Some stakeholders felt that, more often, this was the circumstance of individuals who had lived in nursing facilities for longer periods of time.

2. **Children who need alternate families.** For children, Rider 37 money would follow them back to their birth family or to a group home. Because there was no “foster care” or similar category within the DHS waivers, it was difficult to assist children who needed to live with families other than their birth families to move out of nursing facilities. In situations where children did move in with other families the families could only be paid for a limited number of hours of personal assistance, when they were in fact providing care 24 hours a day, 7 days a week. Likewise, the same circumstances would have made it difficult to assist an adult to move from a nursing facility into the home of another family.

3. **System complexities.** Various system complexities presented challenges for people who wished to move out of nursing facilities. These included:

- Medicaid rules would not allow equipment to be ordered while the person was still in the nursing facility. This often meant a delay for the person to receive the equipment he or she needed for a successful move;
- There were times when a person leaving the nursing facility had no identification cards (e.g., license, birth certificate). Proper identification is necessary in order to receive Social Security and other benefits, and for many other reasons. Replacing these documents took as long as a year;
- Many people expressed frustration with completing extensive paperwork and the lengthy processing times;
- Some people reported delays with the transfer of Social Security benefits, and difficulty finding affordable representative payees;
- Some people reported that the process of having prescriptions transferred to local pharmacies was slow.

4. **Home health care agencies.** Some stakeholders felt that home health care agencies presented a barrier to implementation of Rider 37. The agencies were perceived as reluctant to assist people with greater or more complex support needs (e.g., those with medical needs, with more significant disabilities, with traumatic brain injury (TBI), and with psychiatric disabilities), and were thought to be more likely to deny these individuals eligibility.

5. **Physicians.** People who were interviewed stated that physicians sometimes presented obstacles to community living for certain individuals, but with advocacy were often persuaded to give their consent.

**6. Assumptions and stereotypes.** Family members, home care agencies, physicians, DHS case managers, and people with disabilities themselves often do not believe that it is possible for people with significant support needs to live in their own homes in the community. For this reason, people with greater support needs were sometimes overlooked as candidates for Rider 37. As one stakeholder emphasized, “This calls for a complete paradigm shift regarding a new way of thinking about long-term care; many were not ready or willing to make such a change.”

**7. Greater support needs.** Because funding was capped at individual versus aggregate levels, it was more difficult, if not impossible, for people who had more significant support needs to use Rider 37 to move out of nursing facilities. In some cases, the use of assistive technology saved money by reducing the need for ongoing paid support, making it possible for people with more complex support needs to move into the community.

**8. Accessible, affordable and integrated housing.** Finding accessible, affordable, and integrated housing was a considerable challenge. Because of this, stakeholders felt that the individuals who moved out often had a limited number of choices, if any, about where in the community they could live and may have had to move to assisted living facilities or with families due to the lack of other housing options.

### **Variability of Success with Implementation of Rider 37 within the State**

Although in this small study it was not possible to accurately assess variations of successful implementation in different geographic areas, those who were interviewed were asked to speculate about which factors may have led to greater success in some areas. Factors that may have contributed to the degree of success in a given area include:

- having funded relocation projects;
- good infrastructure of community supports, which characterizes urban areas versus rural ones; and
- good collaboration and networking between community service providers.

Stakeholders suggested that, when looking at “success,” it is important to consider not only the number of people who moved out of nursing facilities, but to examine the types of housing into which they moved, the range of choices they had about their housing, as well as the quality of the assistance they receive. Some interesting patterns emerged from the Rider 37 data by region and living arrangement; these may merit further study.

For instance, there was wide variation among regions in the number of people who moved, ranging from 45 (Region 10) to 508 (Region 3). The Dallas/Fort Worth region (Region 3) facilitated the movement of the highest number of people without funded relocation services. Within about half the regions, between 30% and 50% of the people who relocated moved into assisted living arrangements (e.g., referred to as “alternative living/residential care”). Within other regions, greater percentages of individuals moved into their own homes (e.g., Regions 6, 8) or family homes (e.g., Regions 7, 11). Anecdotal evidence from the interviews reveals a positive example of interagency

and community collaboration in San Antonio, experiences with urban/rural differences in community support infrastructure in Corpus Christi and the region around it, and possible systemic challenges in Houston that may warrant further study.

## **Lessons About What It Takes to Make This Happen**

Based on the experiences of those who implemented Rider 37 in Texas, this section describes some of the lessons that were learned. These lessons also serve as recommendations for other states interested in implementing similar strategies.

- 1. Organized advocates.** Advocates played a key role in the Texas success story. They were well organized and unified. They pushed for a response to Olmstead, and raised awareness about the numbers of young people in nursing facilities. As the pilot project was being implemented, as one stakeholder put it, it was important to have “well-informed and persistent advocates” to help “keep it on track.”
- 2. Partnership and collaboration among all stakeholders.** Another critical factor was the ongoing partnership and collaboration between advocates, DHS, and many others. The Promoting Independence/SB 367 Interagency task force, which formalized this collaboration, was a task force with high visibility and powerful influence. On a regional level, the work of the Regional Specialists was enhanced by collaboration among all stakeholders, and in the San Antonio region the collaboration facilitated by the Texas Community Integration Collaborative was believed to contribute significantly to the successful transitions and positive quality of life outcomes.
- 3. DHS’s willingness, flexibility, and financial incentive.** It was very important that DHS had the willingness and flexibility to implement Rider 37 and its associated pilot project. Many stakeholders recognize that a large degree of this flexibility was rooted in financial incentives—in particular, the high vacancy rates in nursing facilities and the fact that DHS is not a service provider. They are hopeful that the success of the effort, including the cost savings, will encourage continued allocation of resources to assist with the implementation of Rider 37 (now Rider 28 see below).
- 4. Legislature’s commitment.** The legislature’s commitment to Rider 37 was critically important. The champions within the legislature who believe in community living and were willing to devote time and effort to promoting this issue helped to nurture the process. Although Rider 37 was not codified by the 78th legislature, language from the 77th legislature’s Rider 37 has been continued in Rider 28 for the next two years.
- 5. CARS funding, transition grants, and Project Access housing vouchers.** The pilot project CARS funding, transition grants, and housing vouchers also played a critical role in implementation of Rider 37; the Community Awareness and Relocation Services (CARS) funding was particularly beneficial for the inclusion of individuals with greater support needs.

## Future Directions

Informants identified the following essential actions to pursue.

1. **Rate capitation at the aggregate level.** Base the cap at the aggregate level to allow more people to benefit from Rider 37. Funding caps on individual plans of care made it difficult to assist people with greater support needs to transition to the community.
2. **Implementation across all departments** Implement Rider 37 across departments, so that it is fully inclusive of children and adults regardless of the type or severity of disability, and across all types of congregate facilities.
3. **Amendments to waivers to better support alternative families.** Make it easier for children to live with and receive support from alternate families when necessary, including amendments to current waivers.
4. **Work toward “closing the front doors.”** Undertake a collaborative effort involving all stakeholders in order to work toward “closing the doors” of admission to nursing facilities, particularly for children and younger adults with disabilities.
5. **Collaborative housing efforts.** Initiate collaborative efforts, both within and beyond the disability field, to create more and better options for affordable, accessible, and integrated housing. The lack of affordable, accessible, and integrated housing, and the long waiting lists, present significant barriers for people who are moving out of nursing facilities.
6. **Continued resources to support transition.** Continue to invest resources in providing support for people to transition to the community. It is a widely held belief that these resources significantly enhance the numbers of people who transition, the timelines for this transition, and the ability to assist those with greater support needs to make the transition.
7. **Strengthening and expanding the community service system.** There are a number of aspects of the community service system that must be addressed. These include:
  - mentor and monitor home care agencies, particularly as they provide assistance to people with greater or more complex support needs;
  - develop more personal assistance services, including person-controlled options, in order to create more choice in the community;
  - increase rates for home care and personal assistance services;
  - decrease the long waiting time for community services; and
  - include, among community services, provision for support of social/emotional adjustment to the community, particularly for people with limited networks and/or those who have lived in institutions for many years.

**8. Conduct further research.** Conduct further research to document community living outcomes and successful strategies and challenges, at the individual and systems level, to supporting children and adults in the community, including those with the greatest support needs.

### **Further Research**

While this small pilot study was limited in its scope, a study such as this can serve as a first step in the identification of critical issues and possible areas of further exploration of Rider 37 and Rider 28. Some of these areas include:

1. Identify individuals with complex support needs (medical conditions, etc.) who have successfully utilized Rider 37/28, in particular, those who have moved into their own homes or family homes. Conduct studies to document successful strategies to support these individuals. Include some examples that illustrate the use of assistive technology.

2. Conduct a longitudinal quantitative study on quality of life outcomes of Rider 37 and Rider 28. This research may help shed light on variance in outcomes based on factors such as:

(a) location in urban versus rural areas; (b) younger versus older individuals; (c) individuals from minority groups; (d) individuals who had the assistance of relocation services versus those who did not; (e) individuals who have a family/social network versus those who do not.

3. Using a nomination process, conduct studies of a selected region (or regions) within the state that offers examples of specific successful strategies or challenges. Possibilities include San Antonio, because of the collaboration that has assisted a high percentage of participants to move into their own homes; Region 11, for illustration of urban versus rural issues; and Houston, for its systemic barriers as well as its future implementation of some of the strategies used in the San Antonio region.

4. Conduct studies to document strategies and challenges in supporting children to transition from nursing facilities and other institutions to family life. This research could incorporate study of the agency, Every Child, Inc., as well as interviews with other stakeholders involved with supporting children to transition from nursing facilities and other institutions to family life.

5. Using a nomination process, conduct a study to document successful diversion strategies for children and adults.

6. Through interviews and surveys, gather further information on the types of housing in which people now reside as a result of Rider 37/28, as well as the range of housing options and choices they were offered.

7. Using a nomination process, conduct studies of innovative home health care agencies, personal assistance services, and other community support agencies to document successful strategies, particularly in relation to individuals with the most complex support needs.

8. Conduct a study involving Independent Living Centers in Texas, Advocacy, Inc., and other stakeholders to document strategies for conducting and funding their relocation efforts.

9. Conduct a study of advocacy strategies through surveys and interviews with individual advocates and representatives of a range of advocacy organizations.
10. Conduct a comprehensive study of comparative costs of nursing facilities and community settings.

## **Conclusion**

The primary catalyst for Riders 37 and 28 was the Olmstead ruling, along with key advocates and other stakeholders in Texas who were committed to responding to the ruling. In this study, there was unanimous agreement about the success of Rider 37—primarily, that it succeeded in offering more independence, choice, and control to 2,022 individuals who lived in nursing facilities. Those who participated in interviews recognized Rider 37 as promoting new and positive experiences of collaboration and resulting in significant learning about strategies and barriers in nursing facility transition. There is a strong sense that the demand for greater independence, choice, and control will continue to increase. At the same time, there is some apprehension about the new Rider 37 that the 78th Legislature (2004-2005) has authorized.

Since Rider 37 was not codified by the 78th legislature, the language from the 77th legislature's Rider 37 has been continued in Rider 28 for the next two years in the DHS appropriation bill. A new Rider 37 includes language that stipulates that when an individual using Rider 28 leaves the waiver program, any remaining funding for the biennium will remain in the nursing facility budget. Because of this, the base number of community waiver slots will not permanently expand as people utilize Rider 28 to move from nursing facilities into the community.

However, those who were interviewed are hopeful that the experience of implementing Rider 37 (now Rider 28) will contribute to future success by increasing the opportunities for independence, choice, and control for all citizens with disabilities in Texas and beyond.

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## **The Authors**

Jay Klein is Director of the Center for Housing and New Community Economics (CHANCE), Institute on Disability, University of New Hampshire; Pam Walker is Research Associate, with the Center on Human Policy, School of Education, Syracuse University; Celia Feinstein is Associate Director, Institute on Disabilities, Temple University; Paula Margeson is Chairperson of the State Independent Living Council in Texas; and Darrell Lynn Jones is Program Training Coordinator with the Community Living Exchange Collaborative at ILRU.

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2323 S. Shepherd, Suite 1000  
Houston, TX 77019  
(713) 520-0232 (voice)  
(713) 520-5136 (TTY)  
(713) 520-5785 (fax)  
*<http://www.ilru.org>*