Institutional vs. Community Services for Individuals with Intellectual/Developmental Disabilities

Summary

The Southern Oklahoma Resource Center (SORC) began operation in 1907 as the State Training School for White Boys while the Northern Oklahoma Resource Center in Enid (NORCE) began operation in 1909 as the Oklahoma Institution for the Feeble Minded. SORC and NORCE are currently the only state run institutions in Oklahoma for people with intellectual (ID) and developmental (DD) disabilities.

The prevailing trend in the United States for individuals with ID is to receive community-based service rather than service in state-operated facilities. The number of U.S. citizens with ID receiving services in public facilities decreased from 146,260 in 1992 to 33,700 by 2010, while the number of U.S. citizens with ID receiving home and community-based services increased from 62,429 in 1992 to 592,070 by 2010.1

In Oklahoma alone, 5,041 individuals are served in the community successfully. Of these individuals, 721 have a diagnosis of profound mental retardation and 714 have a diagnosis of severe mental retardation. In addition, many of these individuals also have other serious medical conditions.

To date, there are 14 states that have closed their institutional-based service facilities completely. According to Dr. James Conroy, Oklahoma is recognized as producing the best outcomes ever seen in transitioning individuals from institutions into community home placements with the closure of Hissom Class Memorial Center in Sand Springs.

Community services have not always been available in Oklahoma and did not exist thirty years ago. Oklahoma’s community service provider network began to develop after the court-ordered closure of the Hissom Memorial Center in 1994 from a class-action lawsuit.

The outcomes of the individuals transferred from Hissom into the community were required, by the court order, to be tracked and monitored by an independent entity. Dr. James Conroy, PhD and President of the Center for Outcome Analysis (COA), a non-profit that performs evaluation, research and demonstration projects in human services and health care services conducted the initial study and follow up studies of the former Hissom residents (class members). COA was founded on the principle that service agencies should be guided by the measurable individual quality of life outcomes of their services and supports and believes that many qualities of life are reliably measurable and should be measured as the ultimate unit of accountability for human services. Over the last 40 years, Conroy has conducted similar studies all over the country and across the world, tracking people who had been moved from institutions into community homes to determine if they are better off.

Of the individuals moved to community residences from Hissom, there was not a single unsuccessful transition, and some of the families that originally opposed the transition now serve as the biggest

advocates of community service and the quality of life that it provides. In many cases those with the severest disabilities showed the most progress. The former head of the Hissom Parent Guardian Association (parent of a son with developmental disabilities) vigorously opposed closing Hissom and is now a vocal supporter of community placements and the quality of life it provided for her child.

Over time, transitioning from institutional based services to community based services will produce cost savings that will free up more dollars to provide better services and more options for Oklahomans with developmental and intellectual disabilities. While community services for the most part are more cost-effective than institutional service, the transition would take place over a multi-year period so the state would have to maintain institutional costs until they are completely closed. However, the estimated $35 million dollars in capital repairs needed for both SORC and NORCE are dollars that could be used to provide direct services to individuals. Every dollar spent on capital repair and maintenance is a dollar that is not going into direct services for people with disabilities. Individuals living at SORC and NORCE currently contribute their Social Security or Supplemental Security Income (SSI) toward their room and board at the institution. These individuals will continue to use their SSI to pay rent or a portion of their rent in the community and those that are able to work do so and can cover costs as a result. Oklahoma has one of the best rates of employment for people with disabilities in the entire country.

Frequently Asked Questions

- Community Provider Certification, Employee Screening & Monitoring of Private Homes
  - The state of Oklahoma takes significant measures to protect individuals who are served in community home settings. Administrative rules (OAC 340: 100-3-39) established “Pre-employment Screening for Community Services Workers” requirements. Before a community services provider hires a new employee, they must meet the requirements of OAC 340: 100-3-39, which include but not limited to conducting reference checks, a criminal history record check (through OSBI), and a search through the OKDHS Community Services Worker Registry.

- The Developmental Disabilities Services Division (DDSD) within the Oklahoma Department of Human Services (OKDHS) has vigorous training requirements for all community-based staff and takes allegations of alleged maltreatment very seriously. Based on accounts from professionals that participate in the quality assurance program DDSD has a no tolerance policy. Each client is assigned a case manager that conducts regular in home checks. In addition, Oklahoma Advocates Involved in Monitoring (OK-AIM) serves as an independent monitoring initiative that involves service recipient and family members as monitors of service delivery. The OK-AIM program brings volunteers into homes to report on living conditions. In addition, the Office of Client Advocacy, an independent entity within OKDHS provides oversight. The Office of Client Advocacy provides advocacy assistance, conducts investigations and maintains grievance programs to promote client safety and independence and the delivery of OKDHS programs and services in a fair, honest and professional manner.

- Types of Community Placements/Services:
  - Movement into the community begins with an open discussion between a DDSD case manager and parents or guardians about the supports that will be required to enable inclusion in the community. Transition plans will be developed for each person based on
their individual needs and preferences. All placements will include 24 hour support and staff to client ratios could be anywhere between 1 to 1 and 1 to 3. Types of community placements include Specialized Homes where individuals could choose to live in the home of a staff member otherwise known as an agency companion placement. Individuals with higher medical requirements will likely choose Medical Support Homes, where additional nursing staff will be available based on the individuals needs. Comprehensive Support Homes are also available for individuals that may require extra staffing for various other needs. There will be the opportunity for existing qualified institution staff to continue to provide services to individuals they are close to in a community setting. It is important to note that none of the individuals currently in SORC or NORCE will be placed in an Alternative Group Home. Alternative Group Homes are generally utilized for individuals with severe behavioral issues and/or individuals that have some type of criminal history and are wards of the Public Guardian.

- Diagnosis Breakdown for Current Community Placement Recipients:

- There are currently 5,041 people with intellectual disabilities being served in the community. Of this population, 721 are people with profound mental retardation, 714 are people with severe mental retardation, 1297 are people with moderate mental retardation, 2047 are people with mild mental retardation, and 262 are people with an unspecified level of mental retardation.

- Former Hissom Memorial Center Resident (class members) Outcomes:

- Dr. James Conroy conducted a 10 year (1990-2000) study on all the residents that were transferred out of Hissom into the community. Dr. Conroy has studied deinstitutionalization in both the United States and worldwide and has found that Oklahoma is recognized as producing the best outcomes in the transition of ID individuals from institutions to a community service setting. The following graph shows the family perceptions of enhanced qualities of life for their loved ones that once lived in Hissom.

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Quality of Life in Community vs. Institutional Placement:

- As Dr. Conroy’s study concluded, quality of life in the community is much higher than in institutions. In 1990, parents of residents of the Hisson Memorial Center in Sand Springs gave only 5 out of 15 various aspects of quality of life a rating of 3 out of 5 points or higher. In 2000, they were asked to assess the same aspects of quality of life and the parents gave all 15 aspects of quality of life a ranking of 4 out of 5 points or higher.3

Community Providers:

- There are currently 110 private community service provider agencies in Oklahoma with representation in all 77 counties.
- These providers offer services ranging from community residential supports to employment services.

Access to Service in Community vs. Institutional Placement:

- Access to health-related professional services in community settings compared to the institution will remain the same, if not improve. Currently in the institutions, clients that require special services have their needs met through professionals who have been contracted outside of the institution to work with them; this will remain the same in the community. Individuals with ID that live in the community will have access to both a doctor and a dentist within their community.

Life Expectancy:

- There is no significant difference in life expectancy between institutional or community service. Mortality studies concluding that mortality rates are higher in the community have been thoroughly discredited.4 In fact, the results of a longevity study conducted by Dr. Conroy on the transition of Pennhurst residents into the community show increased life expectancy.5

Types of Group Homes and Community Services:

- **Specialized Home:** This model involves the individual moving into a home with an individually selected and trained support staff and their family who provide needed supports on an ongoing basis. The individual would have a local physician and dentist.

- **Medical Support Home:** This model involves three or four individuals sharing a home that has around the clock staffing including needed nursing staff. Professional services are provided by contracted professionals and are based on the needs of each individual. Each resident has a local physician and dentist.

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- **Comprehensive Support Home:** This model is available to individuals who have significant needs but who may require less “hands on” nursing than is provided in a medical support home. Three or four people share a home with around the clock staffing. Like medical support housing, professional services are provided by contracted professionals and are based on the needs of each individual. Each resident has a local physician and dentist.

- **Adult Day Services:** These services include supervised health, social, supportive, and recreational services in a structured daytime program. Each center provides a minimum of 4 hours of planned activities daily.

- **Employment Services:** These services provide a variety of work programs to help people become more independent and earn wages. Services include: assessment, job development and placement, as well as on-the-job training and supports.

- **Staff Ratios:**
  - Staff to client ratios in community placements could be either 1 to 1 or 1 to 3, while the staff to client ratio in institutions is generally much higher.

- **Job Opportunities/Support System in the Community:**
  - Oklahoma ranks #6 in the US when it comes to promoting productivity, with at least 33% of individuals with ID working in competitive employment (The Case for Inclusion 2012, United Cerebral Palsy).
  - In Dr. Conroy’s study, he concluded that close to 60% of the former Hissom residents were involved in sheltered, supported, or competitive employment.\(^6\)
  - According to DHS/DDSD, 60 percent of clients who receive employment services are in integrated employment.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Paid Jobs</th>
<th>Community Based</th>
<th>Center Based</th>
<th>Day Program</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Profound MR</td>
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<td>101</td>
<td>80</td>
<td>47</td>
<td>289</td>
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<tr>
<td>Severe MR</td>
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<td>75</td>
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<tr>
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<tr>
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<td>119</td>
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<td>61</td>
<td>1325</td>
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<tr>
<td>Unspecified MR</td>
<td>57</td>
<td>15</td>
<td>30</td>
<td>11</td>
<td>113</td>
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</tbody>
</table>

**Community Based – Volunteer, Training**

**Center Based – Shelter Workshop**

- Individuals with ID will have a greater support system in communities, because they will be surrounded by friends and family. In Dr. Conroy’s study he found that contact with families and friends rose significantly after individuals were relocated from Hissom into the community.

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\(^7\) Data was collected from DHS/DDSD claims data for FY2012.
➤ **Abuse:**

- Abuse can occur anytime and anywhere.
- Unfortunately, cases of abuse occur in institutions just as they do in private settings. However, in community service settings, many make the case that abuse is easier to recognize due to the fact that the individuals come in contact with neighbors and are more engaged in the community. Additionally, many claim that issues of abuse are handled more swiftly in community settings as opposed to institutions where staff involved in alleged cases of abuse are often reassigned to different duties pending often lengthy investigations.
- There are many layers of external oversight in community settings to provide maximum safety.

➤ **Overmedication:**

- The assertion of over use of psychotropic medication in the community is unfounded, and in fact contradicts the real data, which shows the opposite.
- The table from a Conroy study below shows that the use of the psychoactives is lower in community group homes than in any of the congregate and/or medically specialized settings.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Tranquilizers</th>
<th>Anxiolytics</th>
<th>Antidepressants</th>
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<tbody>
<tr>
<td>Institution</td>
<td>20.6%</td>
<td>6.6%</td>
<td>4.3% (n=656)</td>
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<tr>
<td>ICF (Nursing)</td>
<td>32.5%</td>
<td>14.3%</td>
<td>2.7% (n=1131)</td>
</tr>
<tr>
<td>ICF/MR</td>
<td>46.4%</td>
<td>13.9%</td>
<td>9.5% (n=317)</td>
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<tr>
<td>Group Homes</td>
<td>12.8%</td>
<td>2.5%</td>
<td>6.0% (n=670)</td>
</tr>
</tbody>
</table>

➤ **Hospitalization Support from Daily Service Providers:**

- If an individual is hospitalized it is possible for daily service providers to accompany the individual. Such requests are handled on a case by case basis and can be authorized by the DDSD caseworker depending on the needs of the individual and hospital policy.

➤ **Frequency of Community Interaction and Transportation Provisions:**

- During FY2011, 95.7% of former Hissom residents were receiving transportation services and 99.9% of those individuals received their transportation services through DDSD.9
- Dr. Conroy’s study found that there was a significant increase in community integration from 1.8 events per week in 1992, to 8.2 events per week in 2000.10

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