

Focus of Challenges to Transitioning People Out of the Developmental Centers

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Let's start with a success story:

- 2 young adult men who had made excellent progress at Murdoch.
 - autism spectrum disorder (ASD)
 - intellectual impairments
 - history of extreme behavioral challenges

Needed:

- 24/7 supervised living
- Familiarity with needs of persons with ASD
- Behavioral supports (including infrequent but necessary physical intervention for aggression or self-injury)
- predictable daily schedule with special guidelines when changes are required
- assistance with ADL's
- meaningful vocational programs
- some dietary guidelines and preferences (no other acute medical needs; multiple behavioral medications had been successfully eliminated at Murdoch, with very positive results)

Placement process

- Person-Centered Plan listed strong preferences and non-preferred events/items. Using results of functional assessments and behavioral programming, clear and essential behavioral guidelines were identified.
- Murdoch notified LME's of placement readiness. Care Coordinators and Case Managers selected. Parents (guardians) actively involved. Provider Agency selected by guardians and LME.
- Director of Provider Agency contacted Murdoch Director to arrange for information exchange and staff orientation.
- Active dialogue between treatment team and provider staff about needs, services, likes and dislikes of individuals, important guidelines.

- Provider arranged to send assigned staff to work side-by-side with Murdoch staff with these individuals for up to 5 days.
- Provider identified residential site, negotiated budget with LME's, requested Murdoch team and guardians inspect residential, vocational, and program preparations. Input respected, and adjustments made.
- One guideline, specifying hands-on interventions (redirection and infrequent Therapeutic Holds) conflicted with agency policy. Respecting Murdoch team's opinion, and after much discussion, agency revised policy for these particular individuals.

- Individuals visit, separately, with primary Murdoch staff.
- First individual moves in, with Murdoch staff remaining to work side-by-side with provider staff for one day.
- Two weeks later, same process for second individual.
- Ongoing follow-up, questions and answers, advice.
- Trial placement status to keep Murdoch as safety net for 90 days.
- Individuals discharged from Murdoch with routine follow-up, doing great!

What made this work?

- Strong Guardian involvement
- Open, easy communication between all parties
- LME receptiveness to negotiate budget, accept Murdoch team's recommendations in addressing intense needs
- Provider was willing to be flexible, put in the time and energy to work with Murdoch to design the optimal placement and program, and have it running from Day 1
- Willingness by LME, provider, to adapt policies when needed (e.g., hands-on interventions due to the specific needs of these individuals)
- Excellent cooperation and teamwork between all parties.

Unfortunately, this is not a typical case

■ Philosophy of the developmental centers

- Admissions committees view the centers as placements of last resort. It is not easy to get admitted into the centers.
- Any person currently residing in the centers could be served in the community if sufficient supports and resources are provided.
- Active and persistent efforts have been and will continue to be made in the attempt to find adequate community placements for those who seek it.

Obstacles to Successful Placement

- **Communication/Collaboration**
- **Issues with Case Management**
- **LME motivation**
- **Private Provider incentive**
- **Community capacity**
- **Supports for extreme needs**
- **Preference for the Center as a residence**

Obstacles to Successful Placement

■ Communication/Collaboration

- LME's need to communicate with providers about those desiring placement; LME's get regular reports from the developmental centers
- Providers need to communicate openings to LME's
- All parties need to collaborate to ensure needs are clearly identified and sufficient supports are arranged to meet all of those needs
- All parties need to maintain this collaboration following placement, at least through the transition period

Obstacles (continued)

■ Issues with Case Management

- Providers can only bill for case management services within 60 days of placement. This is usually insufficient. Thorough transition planning is essential.
- Turnover can be extremely high. Case manager experience and knowledge is sometimes limited. In some cases, the case manager contributes very little in the placement process.

Obstacles (continued)

■ **LME motivation**

- Many have indicated downsizing is a low priority, given other pressing issues. They don't feel they have the time or resources to devote to creating or funding placements. Recent budget cuts have exacerbated this.
- At the same time, many LME's view people as living safely and well within the developmental centers. Given the number of unserved people in their LME, there is a lack of motivation to move people who already have stable services.

Obstacles (continued)

■ Private Provider incentive

- Selective about who they serve. They often receive the same funding for persons of differing need levels. No incentives to encourage “stepping a person down” to a less intensive program and replacing them with a person with greater support needs.
- At times, individuals’ placements are terminated with little or no warning. Other than loss of funding (replaced when another individual is accepted), there is no penalty for doing this. As a result, the state psychiatric hospitals and the developmental centers must serve as a **safety net** for these individuals.

Obstacles (continued)

■ **Private Provider incentive** (continued)

- When additional funding is requested for individuals with high need, they are often told no funding is available, or that the funding request is excessive.
- Some providers will try to serve these individuals anyway, cutting supports to make ends meet, resulting in inadequate service provision. These providers with minimal or inadequate supports can be reimbursed at the same rates as more effective providers.
- Note: Given the need for 24/7 supports, guardians are far more likely to consider an ICF-MR placement than other community options. The limited number of ICF-MR openings impedes downsizing.

Obstacles (continued)

■ **Community capacity**

- Many of the people targeted for placement from Murdoch have extensive behavioral or medical needs. Capacity tends to be geared more for people with less extreme needs.
- Recent incentives (e.g., START) to improve community capacity and crisis management have not had a chance to impact existing community supports.
- The centers continue to receive admission requests from ICF providers, LME's, case managers, and families.
- Paradoxically, while our admissions committees are being told that there are insufficient community supports for these people, we are trying to reassure families of people living in the centers that adequate supports are in place in the community for their loved one.
- Frankly, it's a hard sell for our staff.

Obstacles (continued)

■ **Supports for extreme needs**

- The majority of people living in the developmental centers have extreme needs. Murdoch specific information:
 - Severe/Profound impairment (cognitive or adaptive) – 97%
 - Routine medications – 99.4%
 - Medications/treatments provided (Murdoch, per day): 8,717
 - Psychotropic medications – 37.5%
 - Non-ambulatory – 33%
 - Seizures – 48%
 - Fed by tube – 14.4%
- The developmental centers provide 24/7 residential supports. CAP supports are not designed to provide 24-hour care. Treatment teams and guardians are reluctant to support placement when supports are not adequate.
- Community staff may lack the experience and training of the center staff.

Obstacles (continued)

■ **Supports for extreme needs** (continued)

– Effective use of behavioral techniques

- Since the revision of the regulations regarding hands-on interventions, an increasing number of providers now refuse to use hands-on techniques, such as physical redirection, therapeutic walks, or therapeutic holds.
- This has had a dramatic effect by increasing the number of referrals for admissions and by flat refusals by providers to serve individuals with clear need for these procedures.
- This is a most serious problem. Adding to this, some providers will agree to serve an individual but refuse to provide the clinically appropriate behavioral interventions. The treatment team may determine that placement without adequate supports and staff training is not appropriate. The guardian will typically agree, and eliminate further consideration of the placement.

Obstacles (continued)

■ Preference for Murdoch as a residence

– “Aging in place”

- The average age of our general population is 52 years.
- 72 % are aged 46 or above; 13% are aged 66 or above.
- For most people, Murdoch has been their home for decades (average duration = 24 yrs), and they and their guardians/families are happy living there.

– Location of community placement alternatives

- Available residential and day programs are not always in the person’s home community. Guardians/families typically want placement near home if not in the developmental center.

Obstacles (continued)

■ Preference for Murdoch as a residence (continued)

– **Stability, longevity, and quality of supports**

- Guardians report seeing community supports as being less secure. A private provider may close their group homes, or sell them to a company less committed to quality supports. Even with ongoing updates on community options, fewer than 10% of our guardians will even consider placement.
- The developmental centers are viewed as safe and committed to person-centered programming, with well-established advocacy programs, Human Rights Committees, and continuous quality control protocols.
- Staff turnover at the developmental centers is typically lower than in the community.
- The developmental centers have a variety of trained and experienced professionals, clinics, and specialists on staff.
- Access to supports is viewed as more comprehensive. Community providers sometimes don't have ready access to professionals, or may not provide supports in a timely manner.

- **In conclusion, while working through these obstacles, the developmental centers will continue to be committed to persistently pursuing adequate community placements for those who seek it.**
- **At the same time, admissions committees will continue to treat the centers as placements as last resort, serving as “safety nets” for only those persons of significant need with no other option.**

■ **Email example from a large provider agency:**

Thanks Aleck. I think I know who you are talking about and her mother was pushing that admission. I checked around when I got back and you would be happy to know that the response I got back was "It would be easier to get to the moon without a rocket than to get someone in Murdock!"

Keep up the good work.