



Keeping the Promise

True Community Integration and the Need for Monitoring and Advocacy

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November 2011

NATIONAL
DISABILITY RIGHTS
NETWORK

Protection & Advocacy for Individuals with Disabilities



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www.ndrn.org



Cover Photo

Staff with Disability Rights North Carolina met Ty after it received a complaint that he was being overmedicated in a hospital. A P&A staff attorney who visited him there reported that he appeared extremely sedated and was having difficulty breathing. In fact, he was unable to keep his eyes open for more than a few seconds, had a tremor in his hand and had great difficulty with the simple task of raising his arm. The attorney immediately sought to have Ty transferred to another hospital, where over time he improved to the point he was dancing and singing in the hospital's band. With the assistance of Advocate Karen Murphy (standing next to Ty in this photo) and other staff with Disability Rights North Carolina, Ty was discharged to a home in the community. Ty reports he loves his group home. He sings in his church choir, plays drums in a band at the church and is going to the local community college. Best of all, Ty has a girlfriend, and they are looking forward to marrying in the future. Ty is very proud of his story of survival and success, and is happy to share it with anyone who wants to hear more!

A Letter from the Executive Director



More than 10 years ago, the Supreme Court in *L.C. v. Olmstead* held that the anti-discrimination provisions of the Americans with Disabilities Act are violated if states place individuals with disabilities in segregated institutions rather than more integrated community settings appropriate to their needs. Since then, the Bush Administration with the New Freedom Initiative, the Obama Administration with the “Year of Community Living,” and protection and advocacy agencies across the country have taken action to make the promise of Olmstead a reality.

This report - **Keeping the Promise: True Community Integration and the Need for Monitoring and Advocacy** - is the summary of two community monitoring projects that tracked individuals coming out of large institutions to live in the community. We wanted to know if their lives had improved. Is life better in the community? What new opportunities had they found? Were they safe?

Both P&As found that the individuals moving out of institutions into the community were generally happy with their new homes and enjoyed having more independence and a greater freedom of choice. Yet, the P&As also discovered environmental safety issues in the homes themselves – a hornet’s nest above a doorway, missing glass on a screen door, unlocked cleaning supplies, and an unsanitary broken wheelchair tray. The Alabama P&A exposed a major problem concerning Partlow individuals with highly complex medical needs and took action to stop these transfers until better systems were in place.

Beyond these safety concerns, there were quality of life issues as well. The P&As found some children were not receiving adequate education opportunities, people who wanted real jobs were stuck in day programs doing piecemeal work. The findings demonstrate that institutions can be closed and individuals with disabilities moved into community settings, but their quality of life can be no more independent and integrated than their lives in institutions unless community integration efforts include P&A monitoring and advocacy.

Individuals with disabilities and their families were promised that moving into the community would mean fuller, more integrated lives. We need to keep that promise.

Curt Decker

A handwritten signature of Curt Decker in blue ink, written in a cursive style.

Executive Director
National Disability Rights Network

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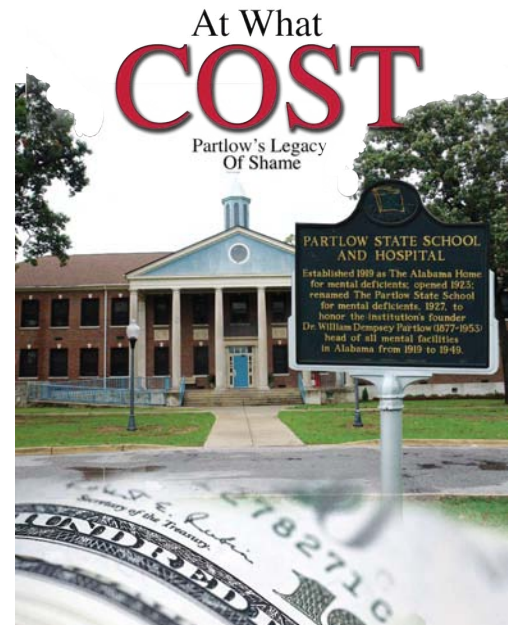
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Introduction

The National Disability Rights Network (NDRN) received \$100,000 from the Administration of Developmental Disabilities (ADD) of the U.S. Department of Health and Human Services to contract with two protection and advocacy (P&A) agencies to monitor at least 20 community settings (6 or less residents with intellectual disabilities) and provide advocacy to at least 10 individuals identified through the monitoring process. NDRN also managed the project and provided technical assistance to the P&As throughout the project. Fourteen P&As responded to NDRN's request for proposals. The contracts were awarded to the Alabama and North Carolina P&As.

The Alabama Disabilities Advocacy Project (ADAP, the Alabama P&A) proposed to monitor 40 community settings and provide advocacy to at least 10 residents in those settings. ADAP had previously issued a report calling for the closure of the Partlow State School and Hospital, the state's last public institution in which people with developmental disabilities (DD) and/or intellectual disabilities (ID) are segregated from their home communities. The report indicated that the costs of Partlow were soaring while residents were living in filthy and neglectful conditions. The P&A documented the human cost of keeping Partlow open: inadequate medical care and inappropriate behavior supports; unsafe, unsanitary and unacceptable environmental conditions; no privacy or freedom of choice; isolation from the community; few opportunities for recreation and leisure; and limited vocational training and work opportunities. Partlow is scheduled to close on November 30, 2011.

ADAP's intent was to follow individuals transitioning from Partlow to the community since the state of Alabama decided to close Partlow shortly after the P&A was awarded the monitoring contract. During the course of the project, ADAP monitored 41 community settings, including community settings where former Partlow residents lived. To prepare for such transitions, the P&A routinely participated in at least two meetings in advance for the purposes of transition planning and assuring a quality exit. Thus, for any single transitioning person, ADAP usually saw the person with DD/ID for a third time when s/he had moved to a new home in the community.



ADAP's Report Calling for the Closure of Partlow
<http://www.adap.net/Partlow%20Report%202012-8-08.pdf>

Residents reported to both P&As that they were generally happy in their new homes and enjoyed their greater independence and freedom of choice.

Disability Rights North Carolina (DRNC, the North Carolina P&A) committed to monitoring 26 community settings and advocating for 10 individuals in those settings. They did even more. During the seven-month project, DRNC staff visited a total of 31 community settings where six or fewer people with developmental disabilities resided. They interviewed a total of 82 individuals with developmental disabilities – seven of whom were transitioning from an institution into the community setting – and a total of 56 people employed in these settings. The P&A focused on community settings that had regulatory histories or that family and community members suggested they monitor. DRNC discovered safety and rights violations in six of the settings and staff either provided or are continuing to provide advocacy to residents in 17 of the community settings, five of which have residents transitioning out of institutions.

During the course of the project, residents reported to both P&As that they were generally happy in their new homes and enjoyed their greater independence and freedom of choice. But many wanted more...ways to communicate with others, real jobs, and the ability to learn new things.

The appendices to this report contain the executive summaries of the final reports from the Alabama and North Carolina P&As. We have highlighted some of the examples from the reports in the pages that follow.

Residents Say that Their Lives in the Community are Better than in the Institutions

Disability Rights North Carolina visited a young man who had been discharged from a state-operated psychiatric facility in January 2010. He was very satisfied with his new life in the community. He loves music and was eager to tell the P&A advocate about his experience recording a CD of his own new songs. He enjoyed learning new things and liked spending time with his girlfriend. But, he wanted even more freedom and independence...he wanted a driver's license. The P&A advocate helped him develop his own self-advocacy skills. Together, they identified the date of his next treatment planning meeting and discussed how he could approach the team about taking a driver's education course.

The Alabama Disabilities Advocacy Program monitored conditions and quality of life issues at a group home where three former Partlow residents lived. The P&A reported that all of the residents were receiving appropriate services, supports and other assistance, including lifts so that they could transfer from their wheelchairs. One of the residents said that she liked her new home better than Partlow. She told the P&A advocate that she liked having choices - she could go to bed when she wanted, choose what she wanted to eat, and spend her money as she liked. One of the staff members in the home, who had previously worked with two of the individuals when they lived at Partlow, said that all three clients had transitioned well into the community placement.

Another former resident of Partlow now lives in a two-bedroom home. His brother/guardian did not approve of the group home originally chosen for the individual and plans were made to move the individual even before ADAP scheduled a monitoring visit. ADAP staff visited him several times in his new community home and found his behavior had improved significantly in the new setting and his medical condition was under better control than before.

One resident told the P&A advocate that she liked having choices. She could go to bed when she wanted, choose what she wanted to eat, and spend her money as she liked.

One of the staff members in the home, who had previously worked with two of the individuals when they lived at Partlow, said that all three clients had transitioned well into the community placement.



Environmental Safety Hazards

The two P&As uncovered a few safety issues during their 72 monitoring visits to community homes of former institutional residents. They were able to quickly eliminate the safety concerns they discovered.

- **Hornet's Nest and Glass Missing in Storm Door.** During an initial monitoring visit, an advocate from Disability Rights North Carolina discovered that a patio storm door was missing the entire glass insert and there was a hornet's nest above the threshold. A staff person told her that the door had been broken for five years! The advocate immediately spoke to the residential manager and the door was fixed and the nest removed.
- **Potentially Dangerous Neighborhood.** Most of the homes that the P&As visited were located in clean and safe neighborhoods.



But, when an advocate from the North Carolina P&A went to visit a home where two children lived, she saw debris littering the street and was approached in a threatening manner by four adult males. The home itself was clean and spacious, but the neighborhood did not seem safe. The advocate followed up with the program coordinator to ensure that law enforcement was notified and that police increased patrols on the street to ensure that the children were safe.

- **Cleaning Chemicals Left Out.** The North Carolina P&A discovered an unlocked closet containing cleaning supplies. As a result of the P&A's advocacy with the home manager, the closet was locked.
- **Unsafe and Unsanitary Equipment.** A North Carolina P&A advocate observed that a resident's wheelchair tray had a hole in it and foam padding was exposed. The resident, who is 64-years old, had spent more than 50 years in the state

developmental center until he was discharged into the community. Staff reported that the broken wheelchair tray was unsanitary because he puts his hands in his mouth after touching the smelly foam. The P&A advocate worked with the resident's case manager to order a new wheelchair tray.

Medical Issues

The most significant safety issue that arose during the monitoring projects was assuring quality of care for persons with medically complex needs at the time of their transition.

As a result of ADAP's advocacy, an outside expert is now involved in the transition of Partlow residents with complex medical needs.

ADAP's support for moves to less restrictive placements in the community has not wavered.

- **Deaths of Individuals with Medically Complex Needs.**

Due to four deaths that occurred in a short period when individuals with medically complex needs were transitioned from Partlow to nursing facilities or hospitals, the Alabama P&A became profoundly concerned about all planned moves of persons with medically complex needs. Before taking further action, the P&A confirmed that responsible family members had consented to the moves of all four individuals after each had been hospitalized multiple times in the preceding year. Though the P&A had not established probable cause for abuse or neglect in any of the four cases as of this date, upon learning of the four cases, the P&A urged the Alabama Department of Mental Health Services (DMH) to postpone all such moves for at least one month and to convene a workgroup to review all planned discharges of all individuals with medically complex needs before making any additional such placements.

As requested by the P&A, the DMH Commissioner immediately ceased all moves of persons with medically complex needs, convened the requested workgroup, and appointed ADAP to the workgroup. The group improved strategies for supporting the moves of individuals with medically complex needs into community settings, including addressing transfer trauma and related issues. The group also improved communication regarding medical information including requiring, at minimum, regular communication between respective medical professionals to monitor the well-being of persons who were and are transitioning.

ADAP also strongly recommended that DMH retain a consultant to improve planning for transitions for individuals identified as medically complex. DMH agreed to retain a consultant as urged by the P&A and contracted with an expert to use the Health Risk Screening Tool (HSRT) for all individuals who lived at Partlow when DMH announced its closure. DMH also obtained technical assistance from the National

Association of State Directors of Developmental Disabilities Services.

DMH resumed placement of individuals with medically complex needs and no one has died since. Although concerned by the deaths, ADAP's support for moves to less restrictive placements in the community has not wavered. In fact, ADAP was one of the first to call for Partlow's closure in their report *At What Cost: Partlow's Legacy of Shame* (<http://www.adap.net/Partlow%20Report%2012-8-08.pdf>).

- **Continuity of Care.** In another case, ADAP discovered that the medications of a former Partlow resident had been changed by his community physician after he moved into the community. At the time of his discharge, Partlow records noted that his medication should not be changed because he metabolized medication very quickly and his current dosage kept him stable. After the medication change, the individual required emergency hospitalization at a psychiatric unit at a local hospital. ADAP is working on both an individual and systemic level to make sure that there is continuity of care when individuals are discharged from Partlow.



Hospital in Tuscaloosa, AL

Communication Issues

During the monitoring visits, the P&As discovered that many individuals were “non-verbal” and could not tell the P&As what they needed. More than likely, these individuals also had communication issues when they were in large state-operated facilities. Because communication is essential to leading a meaningful and interactive life, the P&As immediately began advocating for communication assessments, services and supports for individuals who had communication issues:

Because communication is essential to leading a meaningful and interactive life, the P&As immediately began advocating for communication assessments, services and supports for individuals who had communication issues

- **Need for Sign Language Interpreter.** During a monitoring visit, the North Carolina P&A met a 17-year-old Deaf youth with an intellectual disability. He had limited speech and knew some sign language. The group home staff also knew some basic sign language but their ability to communicate with him was very limited. The advocate determined the young man had a one-on-one aide who used American Sign Language (ASL) in the school setting, and that he is being readied to move into an adult group home with the same agency. The advocate talked with the Quality Assurance Specialist about obtaining a communications assessment for the young man, and she agreed she would follow up with his guardian about the assessment, saying she believed he would be open to having the assessment conducted. The advocate then followed up by providing specific information to the Quality Assurance Specialist about how to obtain the assessment.
- **Failure to Transition Individual with His Communication Device.** ADAP opened a case on behalf of an individual who had been discharged from an institution to the community without the communication device he had used in the institution. The group home attempted on several occasions to obtain the communication device from the institution without success. The P&A intervened and was able to contact the institution, locate the device and personally deliver it to the individual’s new home.
- **Lack of Communication Services and Supports.** During an initial monitoring visit, the DRNC determined that three out of five current residents had serious communication challenges with no apparent assistive technology or other efforts

to address their communication limitations. This community setting had previously been assessed a penalty for failure to provide appropriate communication services for a deaf resident. The focus of the DRNC advocate's additional work was to improve the ability of these residents to communicate. The advocate spoke with the provider, suggested that a communications assessment be performed for each of the residents, and provided specific information about how to get the assessments completed.

Education Issues

Disability Rights North Carolina discovered that two children were not receiving a free and appropriate public education, as required by the Individuals with Disabilities Education Act (IDEA). The P&A's extensive prior experience and expertise in special education issues helped the students and their families get the services they were entitled to receive:

Children were not receiving a free and appropriate public education, as required by the Individuals with Disabilities Education Act



- **Not Enrolled in School.** DRNC represented a 14-year-old youth who had lived in state-operated facilities for people with intellectual disabilities for 10 years, beginning at age 4. The P&A visited the community setting which he had moved into only a month earlier. Although the staff are still getting to know him and how best to support him, he seems to be adjusting well to his new home. The guardian discovered the week before school started that he not yet been enrolled in the public school and did not have transportation to the school. She got him enrolled and the P&A advocate assisted in getting his transportation needs addressed and secured commitments from the school to complete vocational and assistive technology evaluations, which will be reviewed at the next Individualized Education Plan meeting.
- **No Transition Plan.** In a visit to another group home, the DRNC learned that a student had no transition plan and was receiving her education in a day program, rather than in a school. The advocate is working with the girl and her family to get a transition plan developed with the goal of working in the community, rather than a sheltered workshop.

Employment Issues

During the monitoring projects, both P&As became acutely aware of the failure of providers and service agencies to identify meaningful opportunities to work in integrated settings at competitive wages. Some individuals received employment opportunities at day programs but those programs did not provide integrated work at competitive wages or community-based activities.

- **Segregated Day Programs.** An advocate from DRNC monitored two homes owned by the same provider and heard concerns about two day programs the residents from these homes attend. On one monitoring visit, the advocate heard reports that one resident did piecework tasks at his day program, but another resident watched TV while he was at the same day program. During a follow up call, the provider similarly reported that residents color or watch TV at times during the day program. The DRNC advocate visited the day program, and observed the residents. She did not observe anyone watching TV or coloring but did observe individuals engaged in piecework. Subsequently, the group home where these two residents lived closed, and the P&A advocate inquired about their transitions and followed up with one, for whom appropriate services were not identified in a timely way. The advocate plans to visit his new home and day program to ensure he has the opportunities he needs to make money. At the other day program, which is licensed as an adult day vocational program, the advocate observed that the individual service recipients had nothing to do. In fact, there had been no piecework since the previous year because the program had no contract work. In addition, one resident moved to a new home and had a 40-minute commute to the program. The advocate met with the program's manager and followed up with the individual's guardian, who arranged to have a person-centered plan meeting where he and the advocate would advocate for the resident to have local community-based services including participation in some activities at a senior center.
- **Loss of Work.** ADAP monitored a community residence where an individual with an intellectual disability lived. He was very independent, had good communication skills, and

Providers and service agencies failed to provide appropriate vocational assessments or services so that individuals could work in integrated settings at competitive wages.

worked in a paid position at a food bank. However, he had no work once he moved into the community. ADAP is assisting him in getting vocational assessments, services and supports so that he can get a job in his new community.

Transitions Within the Community

On one of its monitoring visits, Disability Rights North Carolina learned that the owners of the home were having financial problems and the home was closing. A care coordinator for one of the residents suggested that the resident live with his mother or face homelessness when the home closed. As a result of the efforts of the P&A and family members, both residents moved to homes they liked. The guardian for another resident told DRNC that the resident liked his new home and housemates. DRNC plans on continuing to monitor the homes in which the residents live to make sure that they are receiving the services and supports they want.

As a result of the efforts of the North Carolina P&A, both residents moved out of a home with financial problems and into a home they liked.



P&As Fill a Gap in Oversight of Community Settings

P&As are a necessary component in any oversight system of community settings where individuals who are transitioning out of large institutions now live. The P&As, if sufficiently resourced and funded, fill the gap, by monitoring quality of life and other issues in the community and providing advocacy to those who need it.

The P&A is the only independent agency that can provide monitoring and advocacy services in small community settings.

The majority of community settings in North Carolina are licensed and regulated by the state Division of Health Service Regulation (DHSR) to ensure they meet state laws and rules regarding the type of licensure under which the setting operates – for example, group homes or Alternative Family Living (AFL) settings. However, Intermediate Care Facilities (ICF/MRs) are additionally regulated under the federal conditions of participation. The state laws and rules focus on environmental, medical and personal safety issues as well as clients' rights. While DHSR has great authority over the facilities and does cite facilities in violation of these laws and regulations, like many other governmental agencies they are stretched and face a tremendous amount of work with limited resources. In addition, it is important to note that when state legislators began reforming the system in 2000, legislators, advocates, clients and others realized a need for a client advocacy program. While a statute is drafted and published, it has a contingent effective date upon funding and has never been funded, leaving gaps for the individuals living in these settings. And during reform, many of the community agencies that historically conducted advocacy for clients began offering paid services, including residential placements such as the community settings highlighted by the work of this grant, to individuals. The ombudsman program is robust in North Carolina, but focuses only on nursing homes and adult care homes, not small community settings. Therefore, the P&A is the only independent agency that can provide monitoring and advocacy services at the community setting level. P&As are vitally important in ensuring not only health, safety and welfare of the residents of these facilities, but in helping ensure the provision of services and opportunities in these settings is comprehensive, integrated and personally valuable to the individuals.

In Alabama, the majority of community settings are certified

and regulated by the Alabama Department of Mental Health (ADMH). The settings are overseen and monitored by a variety of state and federal agencies. ADAP's experience monitoring community settings is valuable part of the effort to ensure appropriate services and supports, health and safety, and overall welfare of the individuals residing in community settings. Currently ADAP utilizes students with special training and individuals with disabilities to assist with monitoring. However, additional personnel and resources are needed to continue this effort.



Typical home in the community in Alabama

Conclusion and Recommendations

The lives of individuals transitioning from large state-operated institutions to small community settings are safe and better.

As the highlighted examples above and the more detailed reports submitted by both P&As reveal, the lives of individuals transitioning from large state-operated institutions to small community settings are safe and better. Individuals and their families were generally satisfied with their new lives. They liked the opportunity to be more independent, make their own choices and interact with others. However, there is still a long way to go to ensure that they have the meaningful, full lives they deserve. Continuous monitoring by P&As is needed to ensure that hazards and other problems are immediately identified and corrected. But, more importantly, there needs to be P&A advocacy to ensure that individuals have appropriate assessments and services so that they can communicate with others, get the education they are entitled to, and work in real jobs. Other government organizations and advocacy groups monitor facilities, but legally-based protection and advocacy systems can assist individuals to be fully integrated in all aspects of community life as required by the ADA.

To the U.S. Department of Justice:

- In all settlement agreements between the DOJ and States regarding community integration, include a provision that the State will fund the P&A in that State to monitor community settings where transitioning individuals live and provide advocacy to such individuals.

To the Center for Medicare and Medicaid Services (CMS):

- Seek new ways to monitor and ensure that Medicaid community based settings and services are of high quality and person directed. As part of this effort, CMS should view the P&A Network as an official part of their panoply of quality enforcement strategies. P&As are established in every state and territory and already knowledgeable about existing waiver programs. P&As are trained in how to monitor disability service systems and how to design corrective action plans.
- Issue regulations on what settings and Medicaid services,

including pre-vocational services, are community based in order to qualify for use in all Medicaid waiver programs. Similar to the proposed rules the agency released regarding 1915c waivers, by definitively stating what environments are not a home or community setting, CMS will help ensure that the intent behind waivers is fulfilled by providing services in truly integrated settings. For example, CMS criteria that should focus on whether the waiver will support person-centered community services, and not services designed around the convenience of the provider or the consensus of a group.

- CMS and HUD Programs should support the principle that virtually all individuals with disabilities can live in their own home with supports and be employed in integrated settings. To this end, individuals with disabilities should have access to housing other than group homes, and other congregate arrangements that are primarily for people with disabilities.
- Ensure that P&As have immediate access to all surveys and reports, along with supporting information, prepared by CMS, its regional offices, and state Medicaid agencies regarding deficiencies identified in home and community based waiver settings.

To Congress:

- Increase the funding of P&As under the DD and Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act) so that they have the resources to monitor community settings and provide advocacy to the individuals in such settings.
- Clarify that P&As have access to all types of community settings (residential, non-residential, public and private) under the 2000 Amendments to the PAIMI Act.

Appendix

NDRN COMMUNITY MONITORING REPORT

ALABAMA DISABILITIES ADVOCACY PROGRAM (ADAP) – EXECUTIVE SUMMARY October 2011

Introduction

Pursuant to our contract with NDRN, ADAP monitored and advocated for a class of persons and numerous individuals in that class who have a range of developmental disabilities (DD), including intellectual disabilities (ID), who moved from Alabama's last state-run ICF-MR (Partlow) to more appropriate, less restrictive homes in the community.

As it happened, within weeks after ADAP was awarded the NDRN contract, Alabama's Department of Mental Health (DMH) announced it would close the state's last public institution in which persons with DD/ID are segregated from their home communities: <http://www.mh.alabama.gov/Downloads/COPI/PressReleases/PartlowClosure.pdf>. In closing Partlow, Alabama will become the first state in the Southeast to close all of its state-run ICF-MR institutions. Since DMH made its initial announcement this spring, DMH has planned for all remaining residents at Partlow to be transitioned to the community by November 30, 2011.

Monitoring and Advocacy

ADAP committed to monitor 40 community settings and provide advocacy services to at least ten individuals, and we exceeded those numbers. During the course of the project, ADAP monitored at least 41 community settings in which six or fewer persons with DD live, including persons transitioning from Partlow to those community settings. To prepare for such transitions, ADAP routinely participated in at least two meetings in advance for the purposes of transition planning and assuring a quality exit. Thus, for any single transitioning person, ADAP usually saw the person with DD/ID for at least a third time when s/he had moved to a new home in the community.

Generally, ADAP's monitoring efforts in the community reveal that persons are happy in their new homes. Where we identified a potential concern, we opened a new case to advocate for the transitioning individual's legal rights. Examples of our advocacy work include, but are not limited to, assuring that transitioning individuals have:

- Needed AT supports, e.g., assuring the delivery of communication devices, a shower trolley, and other equipment that was not provided to clients as planned,
- Behavior support plans tailored to individuals' strengths and needs,
- Opportunities for employment, especially where persons were employed at Partlow,
- Safety, e.g., appropriate use of gait belts for ambulation,
- Sign language training,
- Medical care, e.g., assuring a pulmonologist follow-up where it had not happened, and
- Diet, e.g., assuring a client's diet would include prune juice to avoid constipation, where juice was not part of his diet when he moved and he was hospitalized for related issues.

Persons with Medically Complex Needs

The most significant safety issue that arose during our monitoring project was assuring quality of care for persons with medically complex needs at the time of their transition. Due to four deaths that occurred in a short period when persons with medically complex needs were transitioned from Partlow to community nursing homes or hospitals, ADAP was profoundly concerned about all planned moves of persons with medically complex needs. Though ADAP has not established probable cause for abuse/neglect in any of the four cases as of this date, upon learning of the four cases ADAP immediately urged DMH to postpone all such moves for at least one month and to convene a workgroup to review all planned discharges of all persons with medically complex needs before making any additional such placements.

As requested by ADAP, the DMH Commissioner immediately ceased all moves of persons with medically complex needs, convened the requested workgroup, and appointed ADAP to the workgroup. The group improved strategies for supporting the moves of persons with medically complex needs into community settings, including addressing transfer trauma and related issues. The group also improved communication regarding medical information including requiring, at minimum, daily communication between respective medical professionals to monitor the well-being of persons who were and are transitioning.

ADAP also strongly recommended that DMH retain a consultant to improve planning for transitions for persons identified as medically complex. DMH agreed to retain a consultant as urged by ADAP and contracted with Karen Green McGowan to use the Health Risk Screening Tool (HSRT) for all individuals who lived at Partlow when DMH announced its closure. DMH also obtained technical assistance from NASDDDS.

DMH has since resumed placement of persons with medically complex needs. Though ADAP expressed profound concern regarding the care of persons with medically complex needs, ADAP's support for moves to less restrictive placements in the community has not wavered. See ADAP's report calling for the closure of Partlow in December 2008:

<http://www.adap.net/Partlow%20Report%2012-8-08.pdf>. In fact, during our project Partlow faced "immediate jeopardy" issues in a CMS investigation and, as a result, almost lost federal funding because of significant concerns regarding quality of care issues at Partlow.

Conclusion

Finally, and in a sadly predictable way, individuals with DD/ID who are moving from Partlow to the community continue to face "Not In My Backyard" discrimination. One municipality near Partlow has sought to prohibit the establishment of any new group home within one mile of any pre-existing group home. In response ADAP has filed a federal administrative complaint, and grassroots advocacy groups are planning protests as we write.

ADAP's expanded Community Monitoring Report follows this executive summary.

FINAL REPORT – MONITORING AND ADVOCACY IN COMMUNITY SETTINGS
(MONITORING #01 – PROJECT OF THE TRAINING AND ADVOCACY SUPPORT CENTER)

Contractor: Disability Rights North Carolina
Reporting Period: July 1, 2011 through September 30, 2011

PROJECT SUMMARY AND CONCLUSIONS

During this seven-month project, two Advocates with Disability Rights North Carolina visited a total of 31 community settings where six or fewer people with developmental disabilities resided. The Advocates interviewed a total of 82 individuals with developmental disabilities – seven of whom are transitioning from an institution into the community setting – and a total of 56 people employed by the facilities. The Advocates discovered safety and rights violations in six of the facilities. They either provided or are continuing to provide advocacy to residents in 17 of the community settings, five of whom are transitioning individuals.

In general, most residents the Advocates interviewed appeared to be living in safe and clean environments. The transitioning individuals that the Advocates interviewed expressed happiness with the community settings where they were living. In many of the settings, where appropriate, the staff members were working with the residents on independent living skills. However, a number of general themes observed during the community monitoring project support the need for continued monitoring of community settings.

Clients’ Rights Committees are not consistently offered by providers. They are required pursuant to a change in state law in 2009; however, due to an Advocate’s work on this project, we learned that rules promulgating the law were never enacted and therefore the statute has never been enforced. The chief of the regulatory arm governing these facilities was not even aware the state law had been changed. We are working collaboratively with the section chief to see that rules are adopted to enforce the statute and, in the meantime, that the regulating agency provides direction to providers as to how they can comply with the statute.

Day programs are not consistently robust and meaningful. Though not included in the grant requirements, we visited several day programs to develop a broader assessment of the quality of life of the residents of the community settings. Our experiences from monitoring in those facilities is informing a project another team at Disability Rights NC is undertaking regarding the quality and legality of the vocational portion of day programs across the state.

The delivery of services to people with ID/DD is inconsistent throughout the state, largely owing to statewide budgetary reductions and decisions by the individual Local Management Entities (LMEs) concerning the allocation of their resources. These quasi-governmental agencies replaced county-operated programs when North Carolina embarked on reforming and privatizing its service delivery system for people with mental health, intellectual and developmental disabilities and individuals with substance abuse treatment needs. The operations and accountability of LMEs is a long-standing issue in North Carolina, brought about by these reforms which were instituted a decade ago and the ever-changing policies implemented since then. These changes continue to cause widespread confusion for individuals with disabilities and their guardians, as well as for the providers of these services. The failures of these reforms and the lack of accountability for the provision of services have been

the subject of extensive review by legislative bodies, investigative journalists and advocates. Disability Rights NC continues to use advocacy, litigation and public policy efforts to address these concerns.

The administrators of the five community settings where safety concerns were noted eventually addressed the causes of the safety risks, but some of them required further prompting from the Advocates before the issue was satisfactorily resolved. One egregious example is the case of Resident G. at ██████████. During the April 25 monitoring visit, the Advocate discovered that his wheelchair tray was broken and unsanitary. The Advocate noticed that the tray had been removed, but not replaced, when she visited G. at his day program on May 16. Despite the Advocate’s efforts, the wheelchair tray was not replaced until August 5 – almost three and a half months after the Advocate discovered the problem and reported it to the program administrator.

Two of the community settings visited closed during the project period due to financial problems. An Advocate monitored the discharge planning and relocation of the residents affected. Due to failures on the part of the care coordinator for the LME, coupled with a limited availability of placements, not all residents were relocated to their ideal setting. Indeed, one guardian reported to the Advocate that the LME’s care coordinator said her son, J., would be homeless unless the mother took him back into her home. The mother is in poor health and is not able to care for her son except for short overnight visits. The Advocate worked with the mother and the LME to ensure J. was properly placed with his existing services intact. J.’s story is described in more detail later in this report.

For a number of the community settings visited, the Advocates noted the residents had less than ideal opportunities for community integrated activities, including those that did not involve other people with disabilities. Further advocacy on community integrated activities was provided to those residents. Conditions that contributed to the lack of outings and activities were budgetary constraints, poorly trained and managed staff, and lack of available transportation.

Two of the transitioning individuals were school-aged and both required continuing advocacy for education and transition planning. For one of these individuals, the community setting administrator was slow to enroll the child in the public school. The child’s parent required substantial assistance from the Advocate to navigate the proper special education procedures and access the educational supports and services for which her child was eligible.

SUMMARY – CURRENT REPORTING PERIOD

During the current reporting period, two Advocates with Disability Rights NC visited eight additional community settings where six or fewer people with developmental disabilities resided. The Advocates interviewed 22 individuals with developmental disabilities -- none of whom were transitioning from an institution into the community setting -- and nine people employed by the facilities. The Advocates discovered safety and rights violations in one of the facilities and either provided or are providing advocacy to the residents in four of the community settings. The facilities monitored by the Advocates during this reporting period were group homes.

Also during the reporting period, two Advocates with Disability Rights NC continued their advocacy efforts for individuals with developmental disabilities residing in 13 of the settings monitored during the first reporting period, four of whom were transitioning from an institution into the community setting.

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