

**ADDENDUM TO JULY 27, 2008 REPORT ON  
THE TRANSITION OF 242 PEOPLE FROM  
METROPOLITAN DEVELOPMENTAL CENTER  
TO ALTERNATE LIVING  
RESIDENCES OF THEIR CHOICE:  
FINAL REPORT**

**EXECUTIVE SUMMARY**

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**OFFICE FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES  
DEPARTMENT OF HEALTH AND HOSPITALS**

**June 26, 2009**

## **EXECUTIVE SUMMARY**

### **ADDENDUM TO JULY 27, 2008 REPORT ON THE TRANSITION OF 242 PEOPLE FROM METROPOLITAN DEVELOPMENTAL CENTER TO ALTERNATE LIVING RESIDENCES OF THEIR CHOICE**

This summary recaps information that supplements the July 27, 2008 Report which chronicled activities by the Office for Citizens with Developmental Disabilities (OCDD) to support 242 individuals during and following their transition to new living settings. The previous document included data and findings related to these initiatives from the period of September 2006 through February 2008. The report focused primarily on the activities of and data from two principal entities/projects – The Greater New Orleans Supports and Services Center (GNO) Transition and Technical Support Team (TTST) and the Partnership in Quality (PIQ) Initiative – both put in place by OCDD to assist individuals and their new service providers in facilitating and maintaining successful transitions. The current report supplements this previous information and updates data from March 2008 through June of 2009. Most former residents of MDC/GNO have now been in the community or other transition settings for approximately two years.

#### **The Transition and Technical Support Team: Activities by the TTST and Outcomes for Individuals**

The Transition and Technical Support Team (TTST) was created to assist individuals with their transitions to new living settings and services; to ensure that needed supports were in place; and to provide technical assistance to individuals, families, and new service providers to support meeting individuals' needs. The team consisted of five employees including a licensed clinical social worker, two staff with a master's degree in psychology, one staff with a master's degree in social work, and a licensed occupational therapist. The TTST initially assisted individuals in preparing for transitions; these activities were described in detail in the July 2008 report and are not recounted here. For over two years, the TTST has continued to track, monitor, and assist individuals post-transition. They have provided training to individuals, caregivers, and service providers. They have provided consultation to caregivers and service providers aimed at helping them meet the behavior support needs, medical needs, and physical support needs of individuals. The TTST has played a supportive role with support coordinators, Qualified Mental Retardation Professionals (QMRPs), private providers, and families. They have continued dialog with and observations of individuals who transitioned from GNO and continued to monitor whether personal outcomes were being met. They have served as additional advocates for individuals. More details on the history of the TTST and initial data are available in the 2008 report. The current report derived from updated outcome data and reports provided by the Transition and Technical Support Team.

#### **Outcomes: Initial and Current Residence (as of June 2009)**

Initially, 134 of the 242 people residing at GNO prior to Hurricane Katrina (approximately 55% of the previous census) moved to community settings. One hundred twelve

of the 242 individuals transferred to private provider services. Sixty-eight persons moved to Supported Independent Living settings utilizing New Opportunities Waiver services (50 persons served by private provider agencies and 18 served by GNO supported independent living services). Fifty-eight persons moved to Community Homes (46 persons served by private providers and 12 served by GNO Community Homes). In the previous report, as of February 2008, of 242 people who moved, 172 persons (or 71%) remained in their initial transition setting.

#### Status and Changes in Residence between Feb. 2008 and June 2009:

- Of 46 persons who initially transitioned to private SIL services, 41 continue to receive private SIL services. One individual moved to a private community home. Three individuals moved to a SSC. One individual died.
- Of the 18 persons who initially transitioned to GNO SIL services, 17 continue to reside there and one person transitioned to a SSC.
- Of the four persons who transitioned to family homes with waiver supports, two remain with families, one person was admitted to a SSC, and one person died.
- The one person who moved to a family home without waiver supports was admitted to a large residential facility.
- Of the 46 persons who moved to private community homes, 37 remain in private community homes. Three moved to an SSC. One person died. Five persons moved from the community home to supported independent living.
- Of the twelve persons who moved to GNO community homes, as of June 2009 eleven remain in the GNO homes and one person moved to a nursing home.
- Of the four persons who moved to large private ICF/DDs, three remain and one person moved out of state.
- Of the 100 persons who initially transitioned from MDC/GNO to another SSC, 70 remain in a center. Seventeen have moved to less restrictive settings (8 persons moved into private SIL setting, 1 person in GNO SIL, 1 person with family, 4 persons moved to private community homes, 3 persons moved to public community homes). Thirteen persons died.
- Of the seven persons who initially moved out of state, six remain out of state and one person moved to private SIL.
- Of the four persons who initially transitioned to nursing homes, two remain, one person moved to a SSC, and one person died.
- Since February of 2008, four persons from the original group of MDC residents died, a total of eighteen persons in the roughly four years since August of 2005 (i.e., four persons from March 2008 through June 2009 and fourteen persons from August 2005 through February of 2008).

#### Data on more community-integrated vs. less community-integrated transitions:

- Since discharge, only eleven persons (less than 5% of the original group of residents) currently reside in a setting more restrictive/less community-integrated than the original transition setting.
- Twenty-four persons (approximately 10% of the original group) currently reside in a less restrictive/more community-integrated setting than the original transition setting.

These data indicate that in terms of total group/total population outcomes, the percentage of individuals who transitioned from GNO to more community-integrated settings has continued to increase over the past two years from initial transitions to June of 2009.

## **TTST Support Activities**

The TTST provided follow-up technical assistance or consultation to all 242 of the individuals who transitioned from GNO. The team served as the OCDD coordinating entity for post-discharge consultation requests on medical issues, behavior supports, adaptive equipment, and other service needs. TTST contacts included face-to-face visits, phone consultation, and “other” services. (“Other” services generally included forms of written correspondence for purposes of conveying information about individuals or relative to assisting in identifying additional community resources.)

In the previous report referencing TTST support activities from September 2006 until February 2008, the TTST had a total of 3,727 contacts relative to supporting former residents of GNO. Over 1,000 of these contacts were face-to-face (n=1,093). This was in addition to nearly 2,000 phone contacts (n=1,987) and 647 other contacts. From March 2008 until December 2008, the TTST had over 500 face-to-face contacts with individuals and a total of nearly 1,800 contacts, indicative of extensive, ongoing monitoring and support to individuals and their current service providers in keeping with their two year mission.

The overall contact rate for this reporting period is consistent with figures from the original July 2008 report indicating comparable productivity and frequency of contacts by the TTST in 2007 and 2008.

In looking at all TTST activities from the inception of the team in September 2006 until the end of 2008, the team has had a total of over 5,500 contacts with individuals, caregivers, or service providers. Over 1,500 of these contacts have been face-to-face. The data indicate extensive efforts relative to continued advocacy, monitoring of persons’ needs being met, and extensive collaboration with caregivers and service providers on behalf of these individuals.

### **Outcomes: Emerging and Continuing Support Needs/Resolution of Referral Problems**

The former residents of GNO were a diverse group of individuals with extensive and very different support needs. As noted in the previous report, most individuals served by GNO had extensive medical or behavioral support needs. The GNO population included a large number of individuals with mild cognitive disabilities and significant psychiatric illness (e.g., schizophrenia, bipolar disorder), individuals with profound intellectual disabilities and significant behavioral challenges including aggression and self-injurious behavior, as well as individuals with significant medical support needs. Many of the related needs issues and support challenges were chronic in nature.

As a result, the expectation is that many former residents will continue to have behavioral challenges and medical support needs with some demonstrated variability - increases and decreases - over time. The expectation is that at any given time some percentage of the group will experience some degree of ongoing problems that were being targeted with additional treatment or supports by caregivers and providers.

Consistent with the chronic nature of medical issues previously displayed by the former GNO residents, 110 persons or over 40%, displayed **medical problems** and required **medical supports** during this reporting period. This was the most frequently observed category of support issues. It is noteworthy that under the Medical/Physical/Safety category, problems relative to positioning, swallowing, physical supports, nutritional supports, and adaptive equipment were rare and this is in contrast with figures presented in the 2008 report. The data

suggest that most of the support needs relative to these issues were addressed during the initial reporting period post-transition from GNO and have remained resolved or that services have remained in place or available to address these issues when they did emerge. Most individuals with Medical Complaints either demonstrated substantial resolution of the problem at the end of the reporting period or had medical supports in place to address them. For the three individuals noted to not have medical supports in place at the end of the reporting period, supports were put in place subsequent to the reporting period. For one person, the medical problem is not resolvable even with supports.

The emergence/re-emergence of problems requiring **behavior supports** was also common during this reporting period consistent with the chronic and sometimes even lifelong presentation of behavioral challenges observed in many former GNO residents. Aggression, self-injury, or other behavioral outbursts were displayed by approximately 20% of individuals during this reporting period. These data speak to the importance of access to behavior support services being an ongoing need for some individuals. With regard to behavior support needs, at the end of the reporting period some individuals with emergent behavioral challenges had problems that reduced in frequency and severity and were at that time considered resolved. Some individuals continued to display problems that had not resolved. Again this is not out of keeping with the historical course of the extensive behavior support needs of many of the former GNO residents.

Among the **“unmet needs,”** lack of satisfaction with social life (reported by 14% of individuals) and vocational opportunities (reported by 7% of individuals) were the most frequently reported issues. Meeting the employment wishes of some individuals has continued to be a challenge. For most persons with expressed dissatisfaction with vocational opportunities or for whom caregivers judged this to be an ongoing concern, TTST monitoring indicated plans in place to attempt to address the need. Barriers for some individuals included minimal employment opportunities in some areas. For other individuals, where opportunities may exist, employers have been unwilling to hire them secondary to a history of previous employment problems or difficulty passing employment background checks. With regard to social life concerns, problem resolution may be difficult in instances in which the individual chiefly wants more contact with a family member who does not reciprocate the wish or in instances in which community social experiences are limited by, perhaps, significant medical support needs which preclude leaving the home setting. While, in some instances, alternative activities and supports might be put in place to improve an individual’s happiness, this does not mean that the person’s wish was actually fulfilled or that the specific requested support is in place. For each unresolved issue, the TTST continued to encourage ongoing efforts to address the issue.

Overall, the data show patterns which are likely to continue. The expectation with this group of persons is that within any given period of time some chronic problems will re-emerge and some new problems will emerge that require supports. Resolution and emergence is likely to show patterns of waxing and waning. This suggests an ongoing need by primary caregivers for monitoring so that appropriate services can be delivered and removed as indicated.

Collectively, the experiences of the TTST over the past almost three years, inclusive of the data presented here, appear to illustrate a few critical points. First, for this group of 242 persons, data indicate general stability for most individuals with regard to living settings. Most persons also display stability or resolution with regard to most medical and behavioral issues. Second, some individuals have chronic problems that require variable support needs over time.

Third, based on historical data from 2006-2008, stable outcomes would be projected to continue for most of these individuals if appropriate supports and monitoring remain in place. Data also indicate significant supports and monitoring on the part of families, consultants, and primary caregivers providing services in ICF/DD settings and Supported Independent Living settings to support these individuals and meet their needs.

### **The Partnership in Quality (PIQ) Initiative – Data from Last Survey**

The second major initiative by GNO and OCDD relative to promoting the safety and welfare of individuals who transitioned from GNO was the Partnership in Quality Project. It involved:

- Identifying (by a stakeholder group during the project development stage) variables critical to safety, support needs, and satisfaction that would be tracked for each person leaving GNO;
- Ongoing monitoring of these variables through site visits at regular intervals post-discharge by an objective, independent, quality agent referred to in the project as “assessors/mentors;” and
- Sharing of the findings of this information with individuals and providers and “mentoring” or providing immediate advisory consultation by the assessor/mentor based on findings to assist with resolving any noted problems.

The process implemented by the PIQ assessors included:

- Review of critical incidents and verification of reporting (utilizing *same* critical events tracked for all individuals);
- Verification of ongoing delivery of special, individualized supports identified as critical for a person prior to discharge (reviewing plans for evidence that supports were in place; tracking *different* supports for different individuals); and
- Completion of a brief satisfaction survey.

The PIQ surveys were completed by external contracted assessors and some OCDD staff not affiliated with the transition process. The project was intended to provide an additional and independent evaluation of safety, access to support needs, welfare, and satisfaction of individuals. Identified issues, areas of reported dissatisfaction, and service gaps noted during the PIQ survey were brought to the attention of current service providers and to the TTST so they could offer additional technical or consultative assistance. PIQ data were also reviewed regularly by TTST staff and respective data sources were cross-matched to ensure issues were not being overlooked. TTST staff attempted to follow identified issues to resolution. Data from the last survey completed and analyzed in spring of 2008 indicate the following:

- Identified Problems by Status between First Phase and Second Phase Assessment - Of the 211 individuals with completed assessments in the second PIQ phase, sixty-four persons (30%) had some identified problem noted in the PIQ assessment process. Of these sixty-four, all had been resolved at the post-survey time of reporting or were discovered to have been incorrectly identified as a problem upon follow-up except for 10 (19% of the 64). The ten unresolved issues all subsequently received TTST follow up and were resolved or actions have been taken toward resolution. These results continue to indicate that the majority of individuals who moved from GNO are doing well relative to this outcome variable.

- Identified Problems with Actions in Place Prior to Second Phase Assessment - Data was analyzed whether problems identified during the PIQ assessments were already known to the TTST and actions to resolve were already in place vs. problems TTST were not aware of and that the PIQ assessment surfaced. These data were used in considering whether the PIQ process provided new information about individuals' needs or provided information redundant to what was obtained during TTST follow-up services. During the second phase of assessment, data collected validated that TTST were aware of most problems before the PIQ assessment. Of the seventeen (29% of) instances in which TTST were not aware of the problem, six lived in Supports and Services Centers where the problem was not assessed to need TTST assistance to address. Five of the seventeen instances involved a person not satisfied with work or family contact which may not have required, in the opinion of the provider, the need to contact the TTST. Thus only six individuals had new problems or acute illnesses developed without the provider accessing TTST assistance.
- Type of problems identified during last PIQ assessment - Most categories indicate single digit percentage rates. The largest category impacted 12% of the individuals assessed and involved critical incident concerns. (The largest category of critical incident concerns involved medication errors – e.g., missed dose of medication).
- Abuse/Neglect Data from Second Phase Assessment - Of the eighteen abuse/neglect allegations, twelve were confirmed (6% of total number of persons assessed) and six were not substantiated. These numbers do not indicate a particular pattern or widespread trend of abuse or neglect, although any substantiated claims are of concern. Lapse of supervision of an individual by staff and verbal abuse were the two most frequent categories in the twelve confirmed incidents noted above. Each alleged incident of abuse/neglect was reviewed and addressed by the appropriate standard external protective services entity.
- Critical Incident Concern Data - Twenty-six individuals had some identified recurrent critical events/incidents. The events covered a small number of categories including behavioral incidents (aggression or self-injury consistent with the person's historical problems), medical illnesses, medication errors, and major injuries. The number of individuals identified experiencing these problems was small, particularly in the context of the history of extensive behavioral and medical support needs of previous GNO residents.
- Access to Services Data - A few people were identified during PIQ assessments as experiencing some difficulty in accessing needed services for complex behavioral and medical needs. The TTST was working to assist the individuals' support teams in obtaining the needed service and providing consultation. These data represent a snapshot in time -- persons who at the time of the survey reported (or were reported by staff) to be having difficulty accessing a needed service.
- Satisfaction – Satisfaction survey assessed individuals' satisfaction with place of residence, roommates, work/day activities, interactions with family and friends, health, community inclusion, and staff. The majority of individuals were satisfied with most areas of their life. Consistent with the previous PIQ assessment, in the current PIQ assessment, the areas in which there was the most dissatisfaction revolved around visiting family and friends. Historically these issues have been difficult to resolve where barriers exist related to willingness and availability of the family and friends. Similarly,

community employment shortages contribute to difficulties in locating desired employment options for some individuals and associated dissatisfaction.

The total number of assessments decreased slightly from first to second phase assessment, principally due to some individuals not being interested in participating in the latter assessment. The percentage of individuals with identified possible problems was roughly comparable across phases of assessments, with slight reduction from first to second assessment. Numbers of individuals deceased was also comparable across assessment periods.

Data for type of problem identified was comparable from first to second assessment except for: a) a decrease in out-of-date physical and dental exams comparing first and second assessment periods; b) a slight increase in abuse/neglect allegations; and c) new problems noted comparing first and second periods. Regarding the drop off in out-of-date medical and dental exams, this was largely related to an over-reporting of out-of-date exams in the first assessment which upon further review were found to be inaccurate. (This was discussed in the 2008 report. For a number of cases in the 2008 report, documentation was not readily available to the assessor at the time of the assessment but subsequent investigation confirmed that annual medical and dental exams had occurred.) As previously noted, data indicate problems occurred for a relatively small percentage of persons in each category area; these problems were not evident for the majority of individuals.

Satisfaction data continue to indicate that most individuals were satisfied with most life areas. In comparing data from the more recent survey with data from the initial survey, most categories showed a modest percentage drop in satisfaction. Some categories show a more pronounced drop. One explanation is that a number of individuals had changes in life circumstances leading to less satisfaction from the first to second assessment. While possible, this explanation does not seem intuitive to the authors of this report in the context of the actual life circumstances of these persons. Another possible explanation is that individuals reported spuriously high rates of satisfaction in the previous survey; upon examination the data reported in 2008 do appear to be somewhat higher than might be expected, particularly in categories where satisfaction rates are 98% or higher. The previous rates might be affected by a “honeymoon” effect when people first left the Center and moved into new settings; overly positive evaluations are sometimes observed in the context of extreme novelty. Another possible explanation is that while individuals were initially satisfied with new environments, in general as people become acclimated to life settings and surroundings, they begin to aspire for more and better experiences. Few people are satisfied with all areas of their lives. Some of the above statistics are more accurately interpretable in the context of qualitative data not visible on graphs. For instance most individuals who reported they were not satisfied with their living environment and with whom they lived expressed this because their preference was to live with family, which for various reasons was not an option. Dissatisfaction of some individuals with day/work activities was not unexpected in the context of ongoing difficulty finding personally enriching work activities for some persons. Some persons report drops in satisfaction in areas of day activities and disposable income when they were previously employed on grounds and later had difficulty finding work and earning money in community settings. Dissatisfaction of some persons with frequency of contact with family and friends has been a common finding in other surveys of this nature. These issues, accessing enriching work and social experiences, are issues that continue to require focus for these individuals, for other persons with disabilities in Louisiana, and for persons with disabilities throughout the country. From a services perspective,

the identification of areas of dissatisfaction by some individuals brought these issues to the attention of their teams and circles of support, affording them an opportunity to work with the person to address their concerns. The process of discussing with persons areas of satisfaction and dissatisfaction and taking appropriate actions to address areas of concern must be an ongoing process if supports are to be person-centered and personally enriching.

### **Concluding Discussion**

The Transition and Technical Support Team and Partnership in Quality Project represented attempts on the part of OCDD and GNO to put in place structures that would work collaboratively with individuals, families, and community providers to better ensure that the individuals who left Metropolitan Developmental Center (MDC) would have needed supports and experience successful transitions. As noted in the 2008 report, the intent of OCDD was for these supportive structures to monitor and promote the welfare of these individuals for a period of two years. This has been accomplished.

The premise behind the two-year timeframe was that it was surmised that, because transitions can be difficult periods as people adjust to new living circumstances, initially individuals transitioning would benefit from these additional supports. It was also felt that new providers, as they were just getting to know individuals, would benefit from regular and ongoing access to information from Center staff who had a wealth of knowledge about these persons and had been meeting their support needs for many years. For persons who had ongoing professional technical support needs, having the TTST in place to provide technical support would allow private providers time to develop additional ongoing resources. But it was felt that a reasonable projection was that after a two year period the current providers should have their own wealth of knowledge about individuals and should have had adequate time to identify any additional needed resources, decreasing the need for TTST supports.

As the end of the two-year TTST involvement drew closer, the team undertook a review of the status of all 242 persons who had transitioned. This review included: 1) current status of each person with regard to general welfare and stability; 2) a determination of which persons had current unresolved problems; 3) a determination of which persons had gaps in terms of needed services to assist in resolving these problems (i.e., some individuals might have an ongoing problem but with supports in place to assist with resolution while others might not); 4) identification of the pattern of referral problems for each person over the past two years in terms of predicting potential future problems – what were salient issues, what were re-emerging issues; and 5) identification of the supports and strategies that had been most critical to serving each person over the past two years and most vital in resolving referral problems – that is, based on two years of experiences what emerged as critical ongoing focuses of supports that were important to or important for that person. The TTST utilized their extensive data on each person as well as PIQ data in conducting these reviews.

This review process resulted in the following findings:

- Most individuals who had transitioned from MDC/GNO were stable in current settings and reported satisfaction with most life areas. (In terms of qualitative data, during the review process the TTST discussed many individuals with significant needs who were flourishing and who were having great successes in the community. While individual case data of this nature only tell parts of the story within the context

of the overall group data, they continue to add to the reported experiences of other states that with adequate supports in place many residents of large residential facilities, including persons with significant medical and behavior support needs, can live safely and happily in the community.)

- Consistent with the historical needs of these persons, at any given point in time, some percentage of these individuals are experiencing a new or re-emerging problem that requires intensive supports from caregivers and providers. These problems may be medical, nutritional, orthopedic, behavioral, or psychiatric in nature. Other problems relate to meeting ongoing needs important for quality of life – employment needs, social needs, recreational needs, self-advocacy needs, community inclusion needs, etc. The intermittent emergence of new or previously existing problems for these persons in the future is to be expected. Most of these problems have solutions with proper supports in place. Providers need to be prepared for the emergence of these problems.
- While most persons who transitioned were able to have their needs met in the initial transition setting, for some individuals the process of changing providers or settings is necessary until a more appropriate match between person and provider/setting is identified.
- For individuals who transitioned to a different Supports and Service Center, access to professional resources was not a problem. For individuals with medical support needs who transitioned to community settings, in most instances medical resources were able to be located in new community settings. For individuals with allied health needs (e.g., OT, PT, equipment needs, etc.) who transitioned to community settings, these resources were generally able to be located, with the GNO Expanded Resource Center Allied Health section contributing in terms of providing services like physical support recommendations, positioning consultation, equipment design. Location of behavioral and psychiatric supports for persons in community settings was more problematic.

This review also led to a series of final activities, on the part of the TTST following this reporting period, which are described in the final pages of this document.

### **Activities Post June 2009: Conclusion of TTST Supports**

In response to the review described above, the TTST began the process of discontinuation of the automatic tracking and monitoring of each individual. For each individual, the team provided written correspondence and phone or in-person contact with individuals, guardians, and providers notifying them that the TTST would no longer be initiating contacts for the purpose of consultation and technical supports. Individuals and providers were also notified that they had the option of contacting the GNO Expanded Resource Center if additional technical assistance or consultation is needed. (The TTST is a component program of the GNO Expanded Resource Center.)

For each person in a community setting, the written correspondence included a brief review of the major consultation and technical assistance issues and major support needs issues (e.g., person unhappy without a job, wants more social opportunities) as identified by the TTST. The correspondence included recommendations from the TTST as to important support needs

that should continue to be a focus in the plans of care of these individuals. Supports that were recommended were supports that significantly assisted individuals once in place, supports that in their absence resulted in the individual experiencing difficulties or major dissatisfaction, and supports that individuals had identified as being important to them. There is a prevention component to these recommendations in that they indicate that continued presence of the supports should mitigate against some future problems and that allowing these supports to lapse would be thought to contribute to greater probabilities of problems emerging. Again the purpose of the final summaries of critical issues embedded within the correspondence was to document for caregivers and providers supports which should remain a focus and to strongly encourage that these services and supports continue to receive emphasis in plans of care and service provision.

Along with the above, an additional strategy was employed for some persons. In conducting the status review described in previous pages, the TTST identified twenty-one individuals receiving New Opportunities Waiver (NOW) services who had currently unresolved problems or issues, who had unmet needs (e.g., individual continues to be dissatisfied with social opportunities, day activities, employment options, frequency of family contact, etc.), or who had some other support gap. For these individuals, in addition to the TTST correspondence noted above, OCDD proposed that each of these individuals would have their Comprehensive Plan of Care (CPOC) revised using the new Guidelines for Support Planning. This process is outlined in the Guidelines for Planning and is designed to promote more comprehensive, community-integrated, and accountable service plans. (Note: The Guidelines for Planning are available at the following link: <http://www.dhh.louisiana.gov/offices/publications.asp?ID=77&Detail=2633>). With the permission of the individual and caregiver, the final support recommendations by the TTST have been or will be added to the CPOCs in an attempt to address any identified gaps of lack of appropriate emphasis in the plans. Of the twenty-one persons with identified gaps, the TTST has participated in CPOC revision meetings for nine persons and the plans were revised consistent with the new guidelines. CPOC revisions meetings for the remaining persons are pending.

In addition to this extra initiative on behalf of these particular waiver recipients, OCDD is currently working on provisions for intensive support coordination which will allow a small number of these identified persons who have very complex needs and extraordinary case management needs to receive additional assistance and oversight from their support coordinators.

These final actions on the part of the TTST have brought to conclusion the over two-year process inclusive of TTST and PIQ activities. All transitioned individuals will continue to receive current services delivered by their providers and support coordinators. All individuals have the option of contacting the GNO Expanded Resource Center or other OCDD service programs to request assistance in the future. This document represents the final installment of the report on the transition of these 242 extraordinary people and their families, caregivers, and providers who will continue to work with them in their pursuit of their personal goals.

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The Transition and Technical Support Team (TTST) was created to assist individuals with their transitions to new living settings and services; to ensure that needed supports were in place; and to provide technical assistance to individuals, families, and new service providers to support meeting individuals' needs. The team consisted of five employees including a licensed clinical social worker, two staff with a master's degree in psychology, one staff with a master's degree in social work, and a licensed occupational therapist. The TTST initially assisted individuals in preparing for transitions; these activities were described in detail in the July 2008 report and are not recounted here. For over two years, the TTST has continued to track, monitor, and assist individuals post-transition. They have provided training to individuals, caregivers, and service providers. They have provided consultation to caregivers and service providers aimed at helping them meet the behavior support needs, medical needs, and physical support needs of individuals. The TTST has played a supportive role with support coordinators, Qualified Mental Retardation Professionals (QMRPs), private providers, and families. They have continued dialog with and observations of individuals who transitioned from GNO and continued to monitor whether personal outcomes were being met. They have served as additional advocates for individuals. More details on the history of the TTST and initial data are available in the 2008 report. This current report is derived from updated outcome data and reports provided by the Transition and Technical Support Team.

### **Outcomes: Initial and Current Residence**

This section (See Table 1A below) presents information on initial and current places of residence (as of June 2009) for the 242 persons who transitioned from MDC/GNO. Initially, 134 of the 242 people residing at GNO prior to Hurricane Katrina (approximately 55% of the previous census) moved to community settings. One hundred twelve of the 242 individuals transferred to private provider services. Sixty-eight persons moved to Supported Independent Living settings utilizing New Opportunities Waiver services (50 persons served by private provider agencies and 18 served by GNO supported independent living services). Fifty-eight persons moved to Community Homes (46 persons served by private providers and 12 served by GNO Community Homes).

**TABLE 1. Number of Persons by Initial and Current Places of Residence**

<b>Place of Residence/Living Setting</b>	<b>Initial Post-transition Place of Residence</b>	<b>Current Place of Residence as of 06/09</b>
SIL/Apt. (private)	46	53
SIL/Apt. (public)	18	20
Family homes w/ waiver services	4	2
Family homes w/o waiver services	1	1
Community Homes (private)	46	42
Community Homes (public)	12	14
Large ICF/DD (private)	4	4
Supports & Service Centers (public)	100	79
Out-of-state family discharges	7	7
Nursing Homes	4	2

In the previous report, as of February 2008, of 242 people who moved, 172 persons (or 71%) remained in their initial transition setting. Previous data also included:

- Forty-seven persons moved from their initial transition setting to a setting that was equally or less restrictive [i.e., waiver recipients who changed from one private Supported Independent Living (SIL) provider to another; individuals in a community home (CH) who moved to a new community home; individuals initially in a Supports and Services Center (SSC) who subsequently transitioned to SIL or a CH].
- Only nine persons were residing in a more restrictive setting than the original transition setting as of February 2008 (e.g., moved from community home to SSC).
- Fourteen individuals died from August 2005 to February 2008, as noted in the July 2008 report, a rate consistent with average mortality rates for persons residing in large Intermediate Care Facility for People with Developmental Disabilities (ICF/DD) facilities. Thirteen of these 14 individuals had transitioned from MDC to SSCs or nursing homes, primarily due to medical support needs.

### **Status and Changes in Residence between Feb. 2008 and June 2009:**

- Of 46 persons who initially transitioned to private SIL services, 41 continue to receive private SIL services. One individual moved to a private community home. Three individuals moved to a SSC. One individual died.
- Of the 18 persons who initially transitioned to GNO SIL services, 17 continue to reside there and one person transitioned to a SSC.
- Of the four persons who transitioned to family homes with waiver supports, two remain with families, one person was admitted to a SSC, and one person died.
- The one person who moved to a family home without waiver supports was admitted to a large residential facility.
- Of the 46 persons who moved to private community homes, 37 remain in private community homes. Three moved to an SSC. One person died. Five persons moved from the community home to supported independent living.
- Of the twelve persons who moved to GNO community homes, as of June 2009 eleven remain in the GNO homes and one person moved to a nursing home.
- Of the four persons who moved to large private ICF/DDs, three remain and one person moved out of state.
- Of the 100 persons who initially transitioned from MDC/GNO to another SSC, 70 remain in a center. Seventeen have moved to less restrictive settings (8 persons moved into private SIL setting, 1 person in GNO SIL, 1 person with family, 4 persons moved to private community homes, 3 persons moved to public community homes). Thirteen persons died.
- Of the seven persons who initially moved out of state, six remain out of state and one person moved to private SIL.
- Of the four persons who initially transitioned to nursing homes, two remain, one person moved to a SSC, and one person died.
- Since February of 2008, four persons from the original group of MDC residents died, a total of eighteen persons in the roughly four years since August of 2005 (i.e., four persons from March 2008 through June 2009 and fourteen persons from August 2005 through February of 2008).

### **Data on more community-integrated vs. less community-integrated transitions:**

- Since discharge, only eleven persons (less than 5% of the original group of residents) currently reside in a setting more restrictive/less community-integrated than the original transition setting.

- Twenty-four persons (approximately 10% of the original group) currently reside in a less restrictive/more community-integrated setting than the original transition setting.

These data indicate that in terms of total group/total population outcomes, the percentage of individuals who transitioned from GNO to more community-integrated settings has continued to increase over the past two years from initial transitions to June of 2009.

## TTST Support Activities

The TTST provided follow-up technical assistance or consultation to all 242 of the individuals who transitioned from GNO. The team served as the OCDD coordinating entity for post-discharge consultation requests on medical issues, behavior supports, adaptive equipment, and other service needs. TTST contacts included face-to-face visits, phone consultation, and “other” services. (“Other” services generally included forms of written correspondence for purposes of conveying information about individuals or relative to assisting in identifying additional community resources.)

In the previous report referencing TTST support activities from September 2006 until February 2008, the TTST had a total of 3,727 contacts relative to supporting former residents of GNO. Over 1,000 of these contacts were face-to-face (n=1,093). This was in addition to nearly 2,000 phone contacts (n=1,987) and 647 other contacts.

**TABLE 2. Transition Technical Support Team Contact Activity Data from March 1, 2008 through December 31, 2008**

<b>Total Contacts</b>	<b>Face-to-Face Contacts</b>	<b>Phone Contacts</b>	<b>Other (Non-Sorted Contacts)</b>
1,793	556	864	209

From March 2008 until December 2008, the TTST had over 500 face-to-face contacts with individuals and a total of nearly 1,800 contacts, indicative of extensive, ongoing monitoring and support to individuals and their current service providers in keeping with their two year mission.

The overall contact rate for this reporting period is consistent with figures from the original July 2008 report indicating comparable productivity and frequency of contacts by the TTST in 2007 and 2008.

In looking at all TTST activities from the inception of the team in September 2006 until the end of 2008, the team has had a total of over 5,500 contacts with individuals, caregivers, or

service providers. Over 1,500 of these contacts have been face-to-face. The data indicate extensive efforts relative to continued advocacy, monitoring of persons' needs being met, and extensive collaboration with caregivers and service providers on behalf of these individuals.

## **Outcomes: Emerging and Continuing Support Needs/Resolution of Referral Problems**

The former residents of GNO were a diverse group of individuals with extensive and very different support needs. As noted in the previous report, most individuals served by GNO had extensive medical or behavioral support needs. The GNO population included a large number of individuals with mild cognitive disabilities and significant psychiatric illness (e.g., schizophrenia, bipolar disorder), individuals with profound intellectual disabilities and significant behavioral challenges including aggression and self-injurious behavior, as well as individuals with significant medical support needs. Detailed descriptions of the complex types of: 1) Unmet Needs, Personal Goals, and Skills Training Issues; 2) Behavior and Psychiatric Support Needs; and 3) Medical Needs, Physical Support Needs, and Safety Issues displayed by these 242 people are discussed in Tables 4a-4c of the July 2008 report and included for easy reference as Appendix A in this current report. Many of the related needs issues and support challenges were chronic in nature.

As a result, the expectation is that many former residents will continue to have behavioral challenges and medical support needs with some demonstrated variability - increases and decreases - over time. The expectation is that at any given time some percentage of the group will experience some degree of ongoing problems that are being targeted with additional treatment or supports by caregivers and providers. The following tables and data provide updated findings from March 2008 until December of 2008 with regard to resolved and unresolved problems. Data are based on referral issues identified by and/or addressed by the TTST over this nine month period; the data provide a useful snapshot of supports issues during an extended period of time.

**TABLE 3A. Referral Problems: Number of the 242 Persons with Post-Transition Support Needs Relative to Problem Category from March 2008 until December of 2008**

<b>Problem</b>	<b>Frequency (Number of People)</b>	<b>Percent* (of 242) with Need Relative to Problem Category</b>
<b>Unmet Needs/Personal Goals/Skills Training Issues</b>		
Job/Employment	18	7%
Social Life	33	14%
Housing	11	5%
Financial/Benefits	5	2%
Community Supports	1	<1%
Unfulfilled Wish	15	6%
Hygiene	3	1%
Communication	0	0%
<b>Behavioral and Psychiatric Support Needs</b>		
Physical Aggression	43	18%
Self-Injury	43	18%
Property Destruction	17	7%
Elopement	8	3%
Conflict over Caregiver Requests	33	14%
Behavioral Outbursts	57	24%
Negative Vocalizations	10	4%
Disrobing	6	2%

Stereotypes	3	1%
Law Enforcement	0	0%
Legal Issues	3	1%
Psychiatric Services	10	4%
Placement Stabilization	30	12%
<b>Medical Needs, Physical Support Needs, and Safety</b>		
Medical Complaint	110	45%
Positioning	0	0%
Swallowing	2	<1%
Physical Supports	6	2%
Weight Control	14	6%
Nutritional Supports	3	1%
Adaptive Equipment Needs	9	4%
Abuse/Neglect	1	<1%

\*Percentages rounded to nearest whole number.

Consistent with the chronic nature of medical issues previously displayed by the former GNO residents, 110 persons or over 40%, displayed medical problems and required medical supports during this reporting period. This was the most frequently observed category of support issues. It highlights that many of these persons have substantial health-related issues. Data from the July 2008 report are not re-attached here for comparison purposes as the different periods/durations of time that constituted reporting periods would make simple numerical or percentage comparisons misleading. However, it is noteworthy that under the Medical/Physical/Safety category, problems relative to positioning, swallowing, physical supports, nutritional supports, and adaptive equipment were rare and this is in contrast with figures presented in the 2008 report. The data suggest that most of the support needs relative to these issues were addressed during the initial reporting period post-transition from GNO and have remained resolved or that services have remained in place or available to address these issues when they did emerge.

The emergence/re-emergence of problems requiring behavior supports was also common during this reporting period consistent with the chronic and sometimes even lifelong presentation of behavioral challenges observed in many former GNO residents. Aggression, self-injury, or other behavioral outbursts were displayed by approximately 20% of individuals during this reporting period. These data speak to the importance of access to behavior support services being an ongoing need for some individuals.

Among the Unmet Needs categories, lack of satisfaction with social life and vocational opportunities were the most frequently reported issues.

Table 3B below lists the same supports-related issues but also includes data on two other dimensions. First, the table shows whether problems that emerged during the nine-month reporting period had resolved to sub-clinical levels by the end of the reporting period. Restated, if the problem had resolved (e.g., missing support was now in place) or had reduced in severity or frequency so that it was no longer a major source of distress to the individual or had minimal impact on the individual’s life at the end of the reporting period, this was scored as “resolved” for the purposes of this data element. Secondly, if unresolved at the time of the end of the reporting period, the TTST reported on whether there were supports in place by caregivers to address the issue. This last column therefore includes the number from “resolved” column PLUS number for whom supports were in place. Data are presented below.

**TABLE 3B. Referral Problems: Number of the 242 Persons with Post-Transition Support Needs Relative to Problem Category from March 2008 until December of 2008 – Resolution of Problems by End of Reporting Period and Supports in Place**

<b>Problem</b>	<b>Frequency (Number of People)</b>	<b>Number of Persons for whom Problem Substantially Resolved by the End of Reporting Period</b>	<b>Number of Persons for Whom Problem Either Resolved or Supports were in Place</b>
<b>Unmet Needs/Personal Goals/Skills Training Issues</b>			
Job/Employment	18	8	11
Social Life	33	28	31
Housing	11	11	11
Financial/Benefits	5	3	5
Community Supports	1	1	1

Unfulfilled Wish	15	7	10
Hygiene	3	3	3
Communication	0	N/A	N/A
<b>Behavioral and Psychiatric Support Needs</b>			
Physical Aggression	43	19	42
Self-Injury	43	12	43
Property Destruction	17	12	17
Elopement	8	5	8
Conflict over Caregiver Requests	33	16	31
Behavioral Outbursts	57	25	55
Negative Vocalizations	10	1	10
Disrobing	6	1	4
Stereotypies	3	1	3
Law Enforcement	0	N/A	N/A
Legal Issues	3	1	2
Psychiatric Services	10	7	10
Placement Stabilization	30	21	27
<b>Medical Needs, Physical Support Needs, and Safety</b>			
Medical Complaint	110	72	107
Positioning	0	N/A	N/A
Swallowing	2	2	2
Physical Supports	6	4	5
Weight Control	14	7	12

Nutritional Supports	3	3	3
Adaptive Equipment Needs	9	8	8
Abuse/Neglect	1	1	1

With regard to Unmet Needs Categories, meeting the employment wishes of some individuals has continued to be a challenge. For most persons with expressed dissatisfaction with vocational opportunities or for whom caregivers judged this to be an ongoing concern, TTST monitoring indicated plans in place to attempt to address the need. Barriers for some individuals included minimal employment opportunities in some areas. For other individuals, where opportunities may exist, employers have been unwilling to hire them secondary to a history of previous employment problems or difficulty passing employment background checks. With regard to social life concerns, problem resolution may be difficult in instances in which the individual chiefly wants more contact with a family member who does not reciprocate the wish or in instances in which community social experiences are limited by, perhaps, significant medical support needs which preclude leaving the home setting. While, in some instances, alternative activities and supports might be put in place to improve an individual's happiness, this does not mean that the person's wish was actually fulfilled or that the specific requested support is in place. For each unresolved issue, the TTST continued to encourage ongoing efforts to address the issue.

With regard to behavior support needs, at the end of the reporting period some individuals with emergent behavioral challenges had problems that reduced in frequency and severity and were at that time considered resolved. Some individuals continued to display problems that had not resolved. Again this is not out of keeping with the historical course of the extensive behavior support needs of many of the former GNO residents. With regard to severity, for those individuals who do display behavioral challenges, the place of residence data presented in a previous section of this report do indicate that in most instances behavior support issues have not reached the level of resulting in loss of placement. Nevertheless, the nature of these behavioral issues is such that for a percentage of former GNO residents, supports to prevent and manage aggression or self-injurious behavior may potentially need to be lifelong. Most persons with these behavior challenges were noted to have supports in place attempting to address the issues. The ongoing unresolved status for some individuals were in some cases indicative of difficulties in finding appropriate resources or emergence of new problems just prior to the end of the reporting period with inadequate time to put supports in place before the end of the reporting period. For those thought to need additional supports to adequately address behavior support needs, there is additional discussion at the conclusion of this report.

Most individuals with Medical Complaints either demonstrated substantial resolution of the problem at the end of the reporting period or had medical supports in place to address them.

For the three individuals noted to not have medical supports in place at the end of the reporting period, supports were put in place subsequent to the reporting period. For one person, the medical problem is not resolvable even with supports.

Overall, the data show patterns which are likely to continue. The expectation with this group of persons is that within any given period of time some chronic problems will re-emerge and some new problems will emerge that require supports. Resolution and emergence is likely to show patterns of waxing and waning. This suggests an ongoing need by primary caregivers for monitoring so that appropriate services can be delivered and removed as indicated.

Collectively, the experiences of the TTST over the past almost three years, inclusive of the data presented here, appear to illustrate a few critical points. First, for this group of 242 persons, data indicate general stability for most individuals with regard to living settings (Table 1). Most persons also display stability or resolution with regard to most medical and behavioral issues (Table 3A). Second, some individuals have chronic problems that require variable support needs over time. Third, based on historical data from 2006-2008, stable outcomes would be projected to continue for most of these individuals if appropriate supports and monitoring remain in place. Data also indicate significant supports and monitoring (Tables 2 and 3B) on the part of families, consultants, and primary caregivers providing services in ICF/DD settings and Supported Independent Living settings to support these individuals and meet their needs.

## **The Partnership in Quality (PIQ) Initiative – Data from Last Survey**

The second major initiative by GNO and OCDD relative to promoting the safety and welfare of individuals who transitioned from GNO was the Partnership in Quality Project. It involved:

- Identifying (by a stakeholder group during the project development stage) variables critical to safety, support needs, and satisfaction that would be tracked for each person leaving GNO;
- Ongoing monitoring of these variables through site visits at regular intervals post-discharge by an objective, independent, quality agent referred to in the project as “assessors/mentors;” and
- Sharing of the findings of this information with individuals and providers and “mentoring” or providing immediate advisory consultation by the assessor/mentor based on findings to assist with resolving any noted problems.

The process implemented by the PIQ assessors included:

- Review of critical incidents and verification of reporting (utilizing *same* critical events tracked for all individuals);

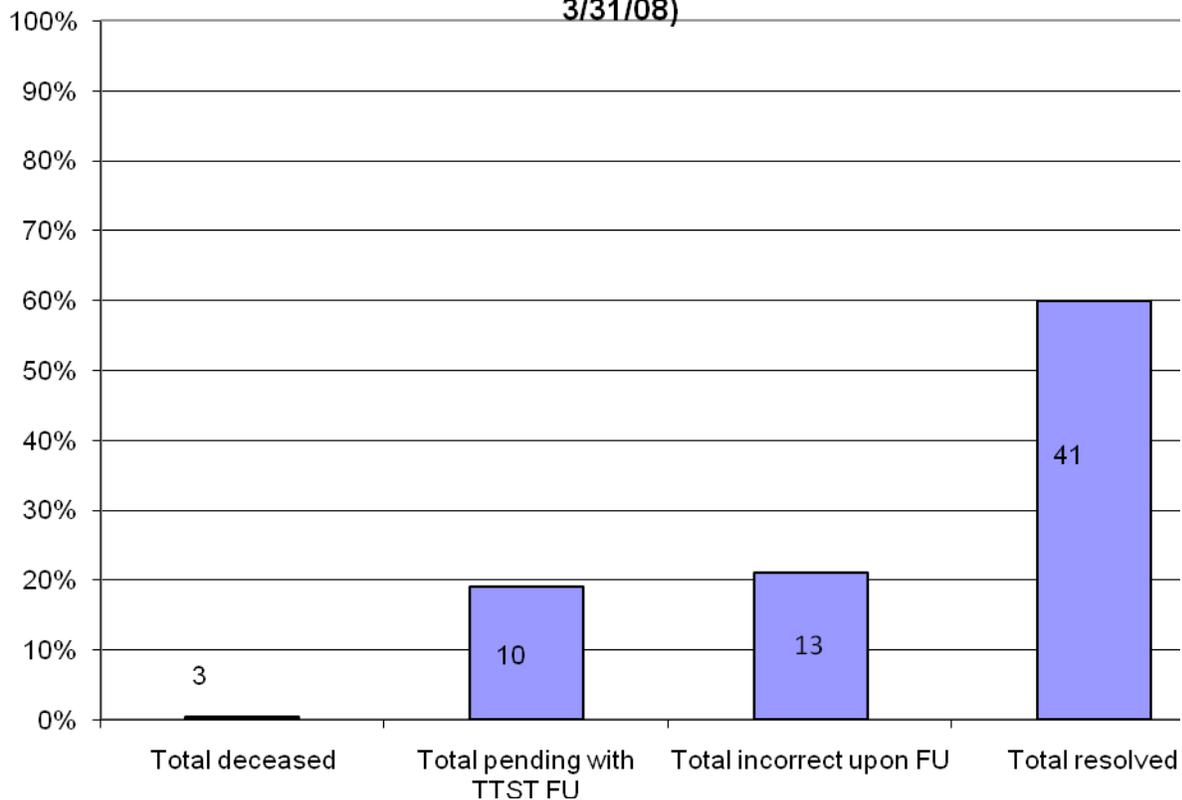
- Verification of ongoing delivery of special, individualized supports identified as critical for a person prior to discharge (reviewing plans for evidence that supports were in place; tracking *different* supports for different individuals); and
- Completion of a brief satisfaction survey.

The PIQ surveys were completed by external contracted assessors and some OCDD staff not affiliated with the transition process. The project was intended to provide an additional and independent evaluation of safety, access to support needs, welfare, and satisfaction of individuals. Identified issues, areas of reported dissatisfaction, and service gaps noted during the PIQ survey were brought to the attention of current service providers and to the TTST so they could offer additional technical or consultative assistance. PIQ data were also reviewed regularly by TTST staff and respective data sources were cross-matched to ensure issues were not being overlooked. TTST staff attempted to follow identified issues to resolution. Data from the last survey completed and analyzed in spring of 2008 are discussed below.

## PIQ GRAPHS

**FIGURE 1**

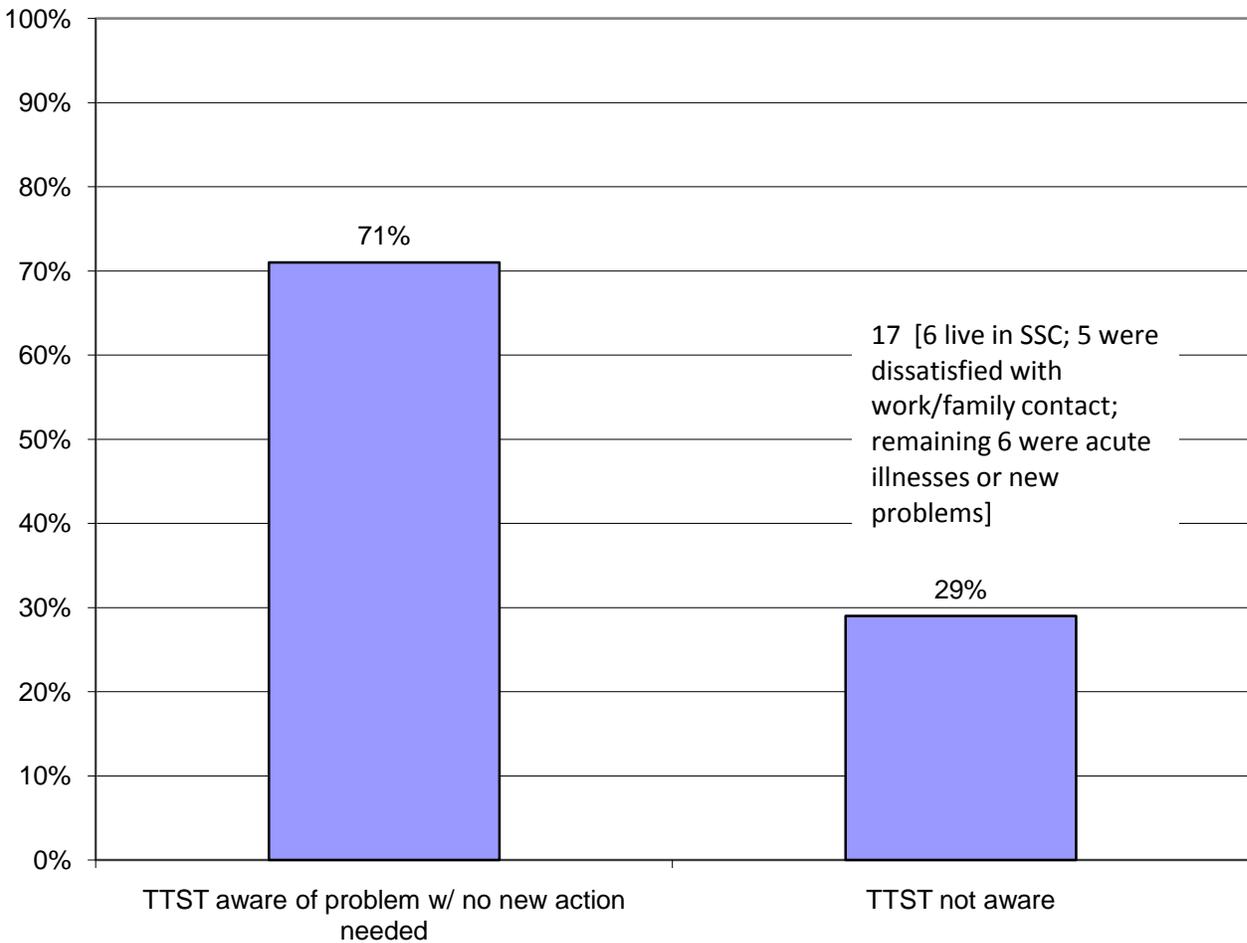
**Percentage of Individuals with Identified Problems by Status  
Between First Phase and Second Phase Assessments (as of  
3/31/08)**



This graph (FIGURE 1) indicates numbers of persons for whom problems were identified during the last PIQ survey and disposition of problems, including resolution of problems by support staff and/or with assistance of the TTST. Of the 211 individuals with completed assessments in the second PIQ phase, sixty-four persons (30%) had some identified problem noted in the PIQ assessment process. Of these sixty-four, all had been resolved at the post-survey time of reporting or were discovered to have been incorrectly identified as a problem upon follow-up except for 10 (19% of the 64). The ten unresolved issues all subsequently received TTST follow up and were resolved or actions have been taken toward resolution. These results continue to indicate that the majority of individuals who moved from GNO are doing well relative to this outcome variable.

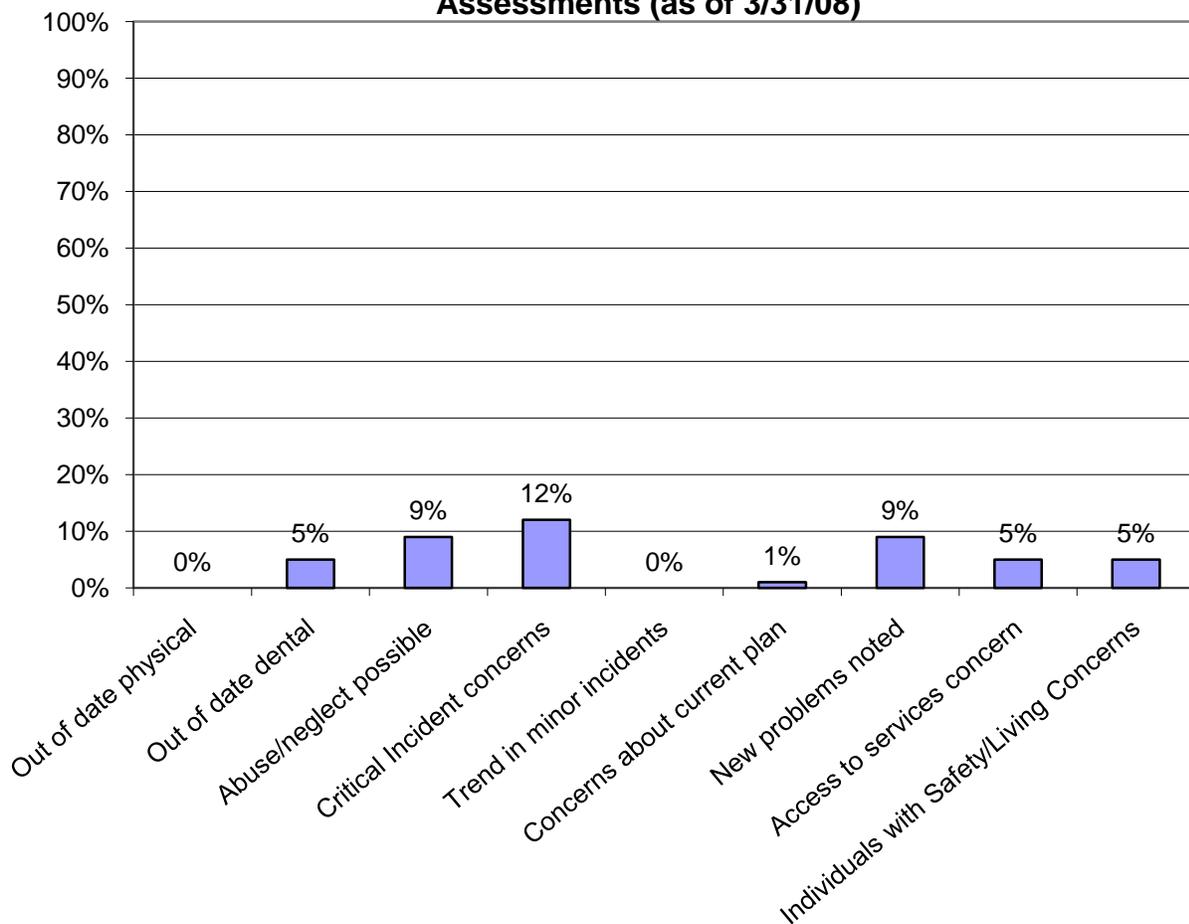
**FIGURE 2**

**Percentage of Identified Problems Known to TTST with Actions in Place Prior to Assessor/Mentor Review at Second Phase Assessment (of the 57 Individuals with Confirmed Identified Problems Other than Medical/Dental Out-of-Date)**



This graph (FIGURE 2) highlights whether problems identified during the PIQ assessments were already known to the TTST and actions to resolve were already in place vs. problems TTST were not aware of and that the PIQ assessment surfaced. These data were used in considering whether the PIQ process provided new information about individuals' needs or provided information redundant to what was obtained during TTST follow-up services. During the second phase of assessment, data collected validated that TTST were aware of most problems before the PIQ assessment. Of the seventeen (29% of) instances in which TTST were not aware of the problem, six lived in Supports and Services Centers where the problem was not assessed to need TTST assistance to address. Five of the seventeen instances involved a person not satisfied with work or family contact which may not have required, in the opinion of the provider, the need to contact the TTST. Thus only six individuals had new problems or acute illnesses developed without the provider accessing TTST assistance.

**FIGURE 3**  
**Percentage of Individuals from GNOSSC with Concerns Noted**  
**by Category Between First Phase and Second Phase**  
**Assessments (as of 3/31/08)**

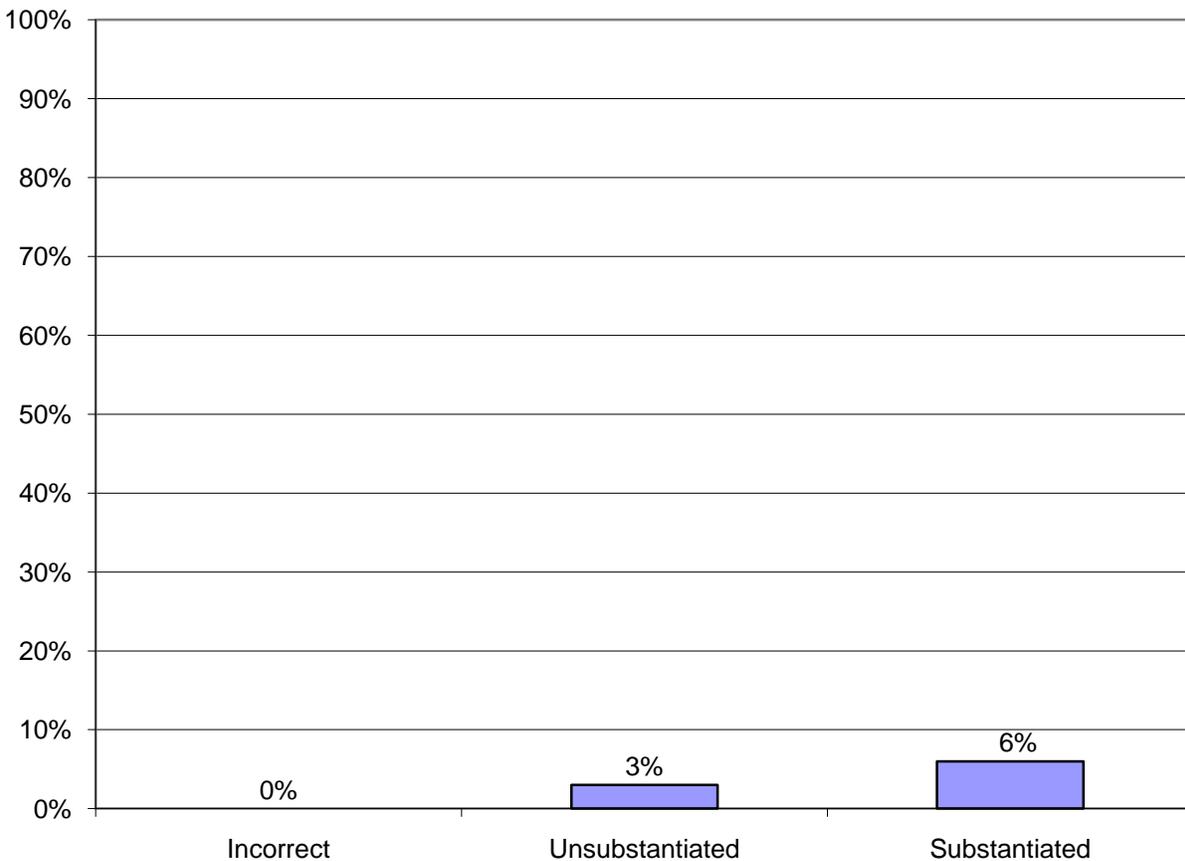


The above graph (FIGURE 3) is a breakdown of the type of problems identified during last PIQ

assessment; it shows percentage of individuals for whom each category of problem was identified. Most categories indicate single digit percentage rates. The largest category impacted 12% of the individuals assessed and involved critical incident concerns. (The largest category of critical incident concerns involved medication errors – e.g., missed dose of medication).

**FIGURE 4**

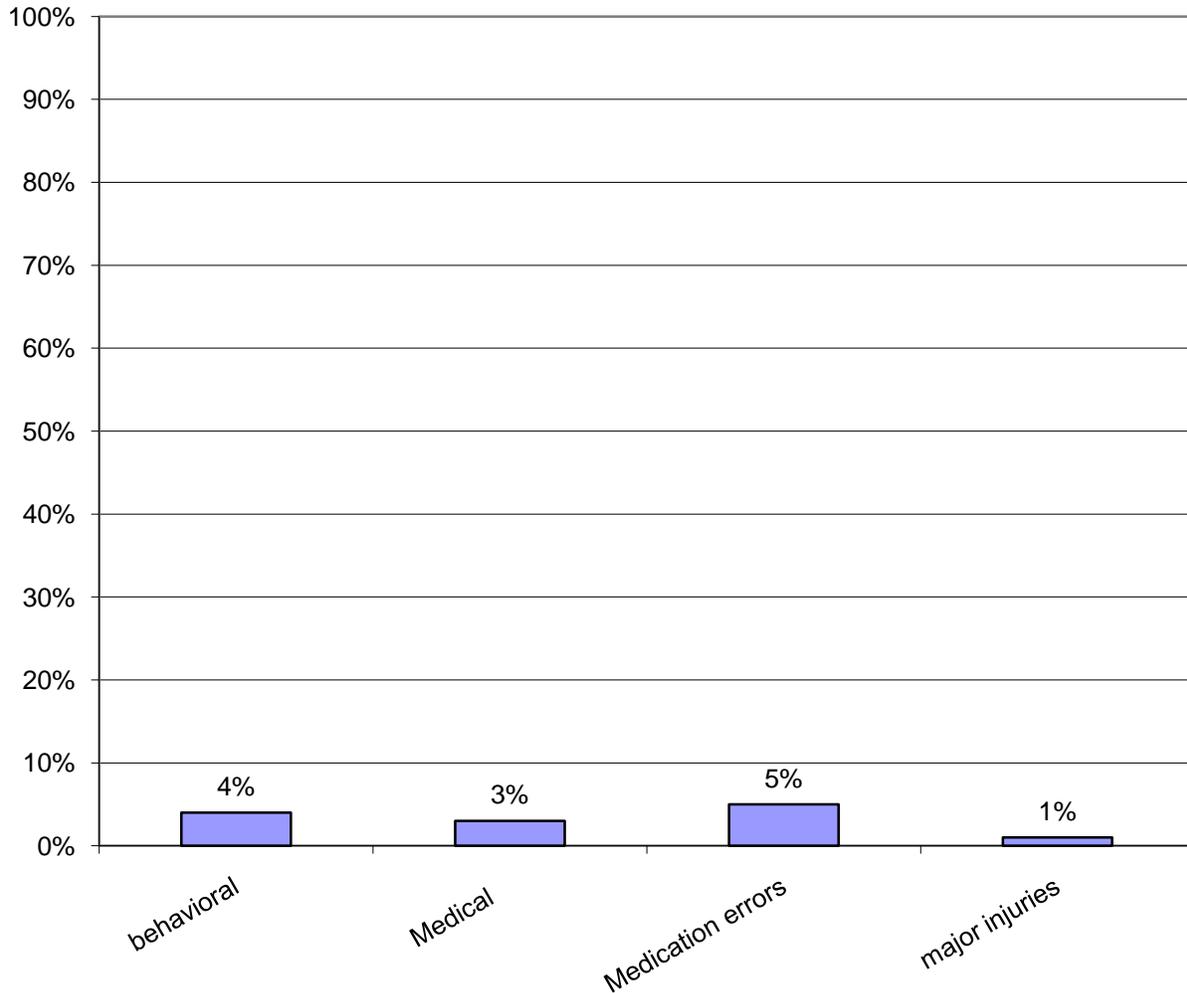
**Abuse/Neglect Data From Second Phase Assessment**



Of the eighteen abuse/neglect allegations, twelve were confirmed (6% of total number of persons assessed) and six were not substantiated. These numbers do not indicate a particular pattern or widespread trend of abuse or neglect, although any substantiated claims are of concern. Lapse of supervision of an individual by staff and verbal abuse were the two most frequent categories in the twelve confirmed incidents noted above. Each alleged incident of abuse/neglect was reviewed and addressed by the appropriate standard external protective services entity.

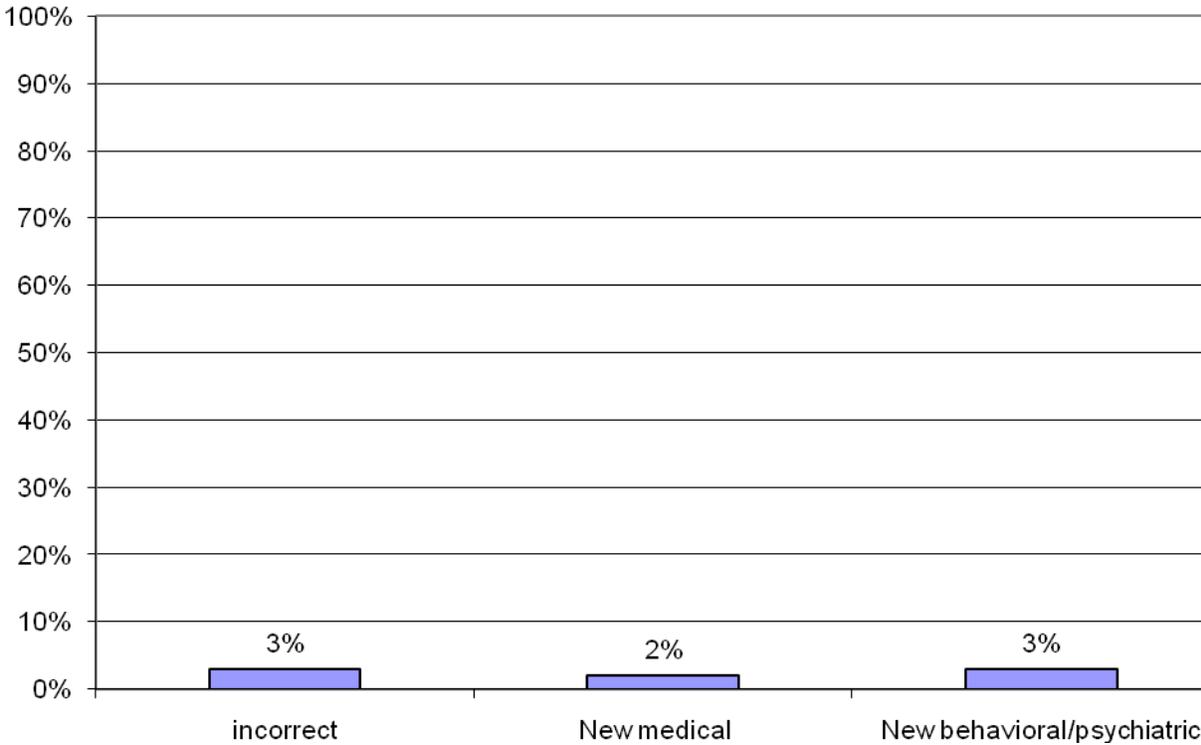
**FIGURE 5**

**Critical Incident Concern Data**



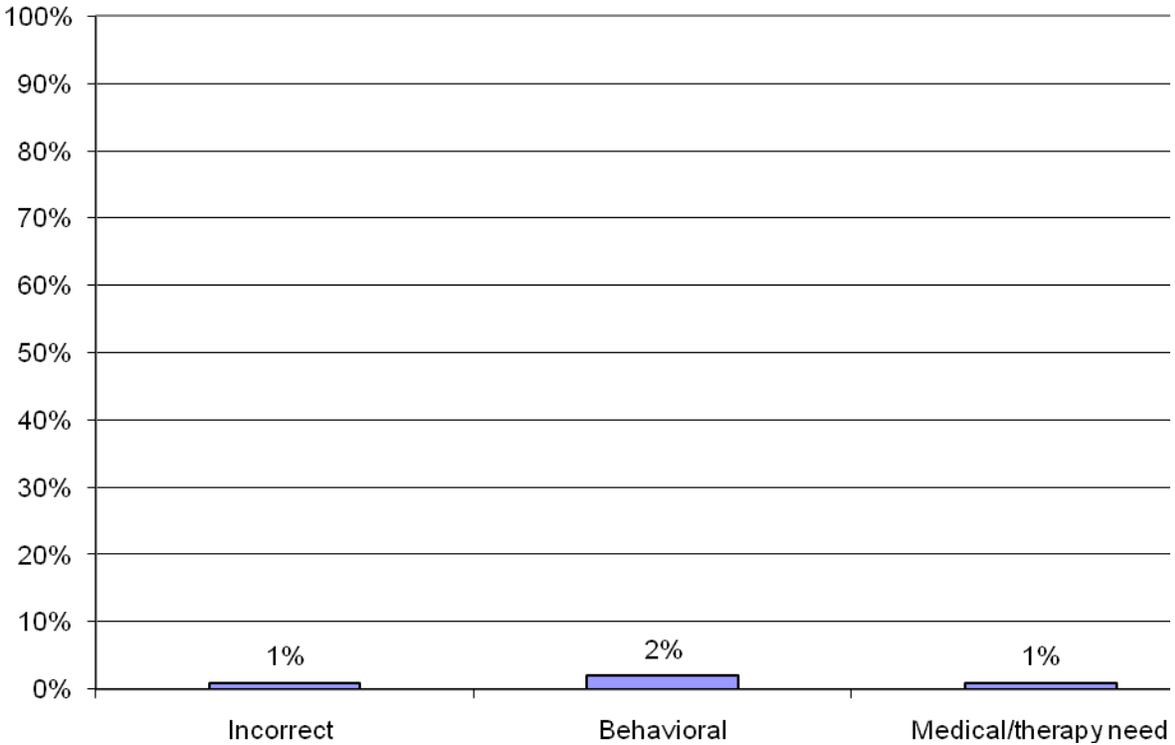
Twenty-six individuals had some identified recurrent critical events/incidents. The events covered a small number of categories including behavioral incidents (aggression or self-injury consistent with the person’s historical problems), medical illnesses, medication errors, and major injuries. The number of individuals identified experiencing these problems was small, particularly in the context of the history of extensive behavioral and medical support needs of previous GNO residents.

**FIGURE 6**  
**New Problems Data**



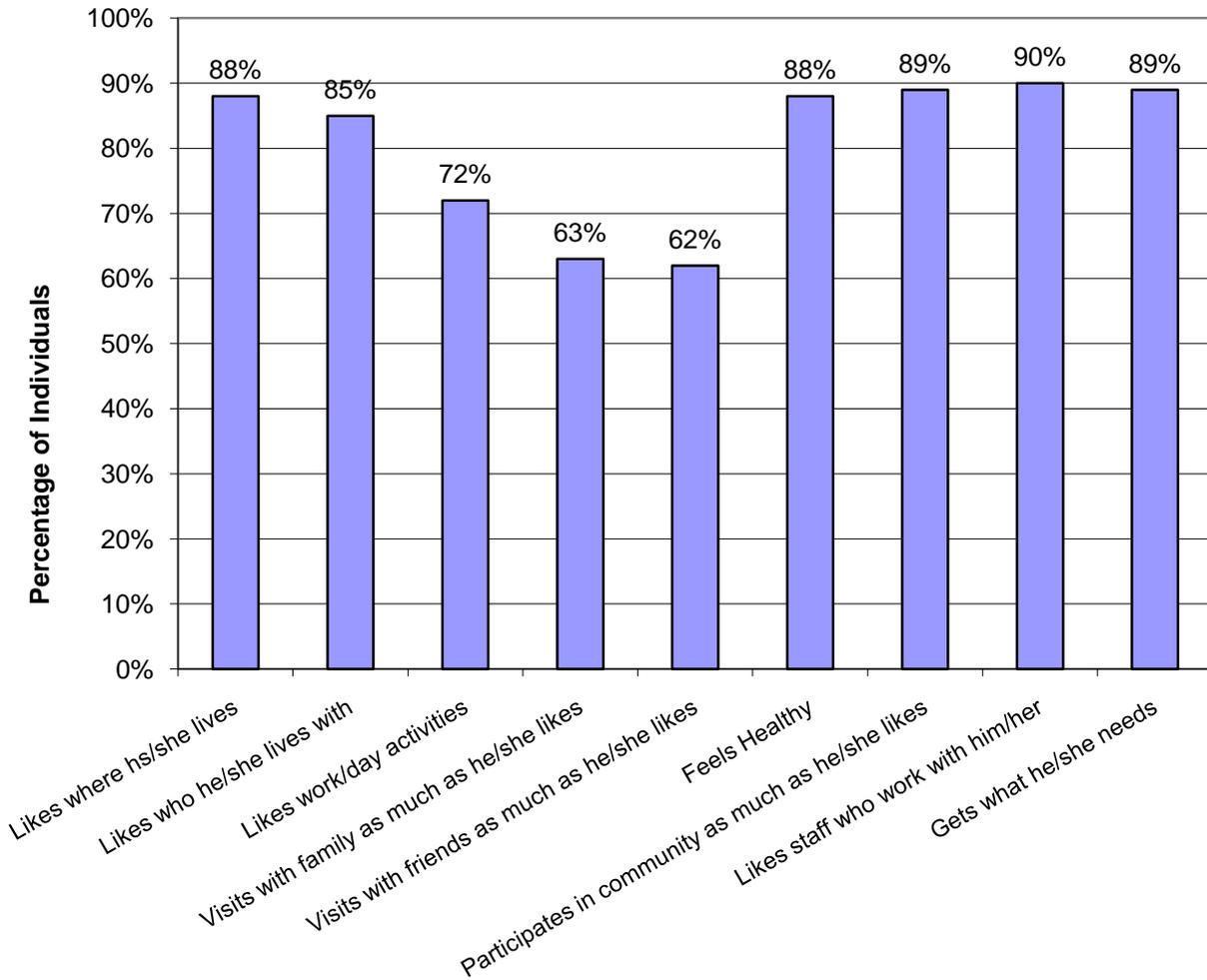
Three percent of noted problems (“incorrect” category) were determined upon follow up to have been incorrectly identified as a problem in the absence of a real issue. A small number of individuals had newly identified problems. The teams were working in each instance to establish the needed supports to address these areas. None of the identified new problems reflected on this graph were the result of neglect or failure to support the individuals.

**FIGURE 7**  
**Access to Services Data**



A few people were identified during PIQ assessments as experiencing some difficulty in accessing needed services for complex behavioral and medical needs. The TTST was working to assist the individuals' support teams in obtaining the needed service and providing consultation. These data represent a snapshot in time -- persons who at the time of the survey reported (or were reported by staff) to be having difficulty accessing a needed service.

**FIGURE 8**  
**Satisfaction**

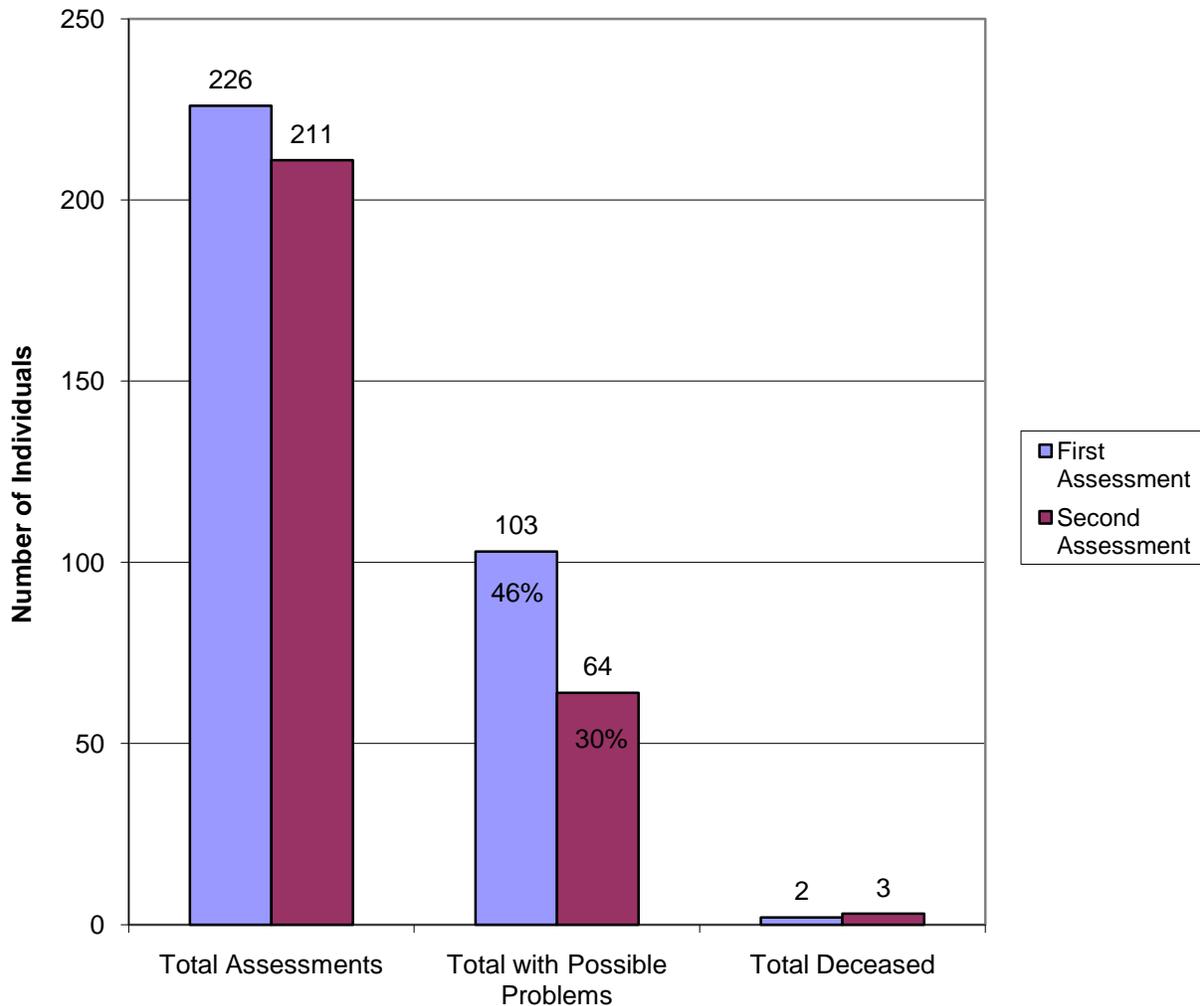


This graph displays individuals' reported satisfaction in various life areas as per the Satisfaction Survey component of the PIQ assessments. The majority of individuals were satisfied with most areas of their life. Consistent with the previous PIQ assessment, in the current PIQ assessment, the areas in which there was the most dissatisfaction revolved around visiting family and friends. Historically these issues have been difficult to resolve where barriers exist related to willingness and availability of the family and friends. Similarly, community employment shortages contribute to difficulties in locating desired employment options for some individuals and associated dissatisfaction.

The following graphs represent comparisons between the first and second phase assessments.

**FIGURE 9**

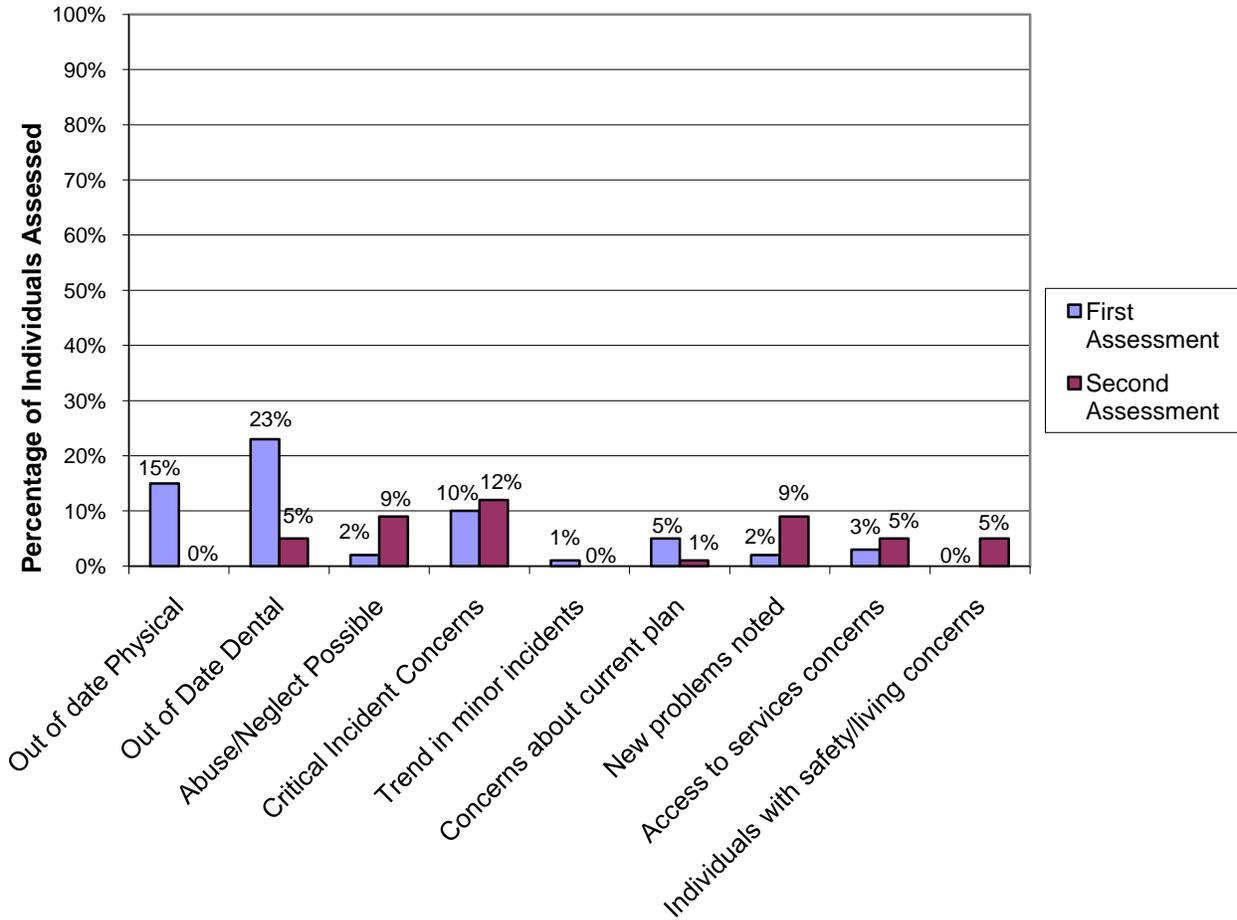
**Comparison of First and Second Phase Assessments for Partnership in Quality**



The total number of assessments decreased slightly from first to second phase assessment, principally due to some individuals not being interested in participating in the latter assessment. The percentage of individuals with identified possible problems was roughly comparable across phases of assessments, with slight reduction from first to second assessment. Numbers of individuals deceased was also comparable across assessment periods.

**FIGURE 10**

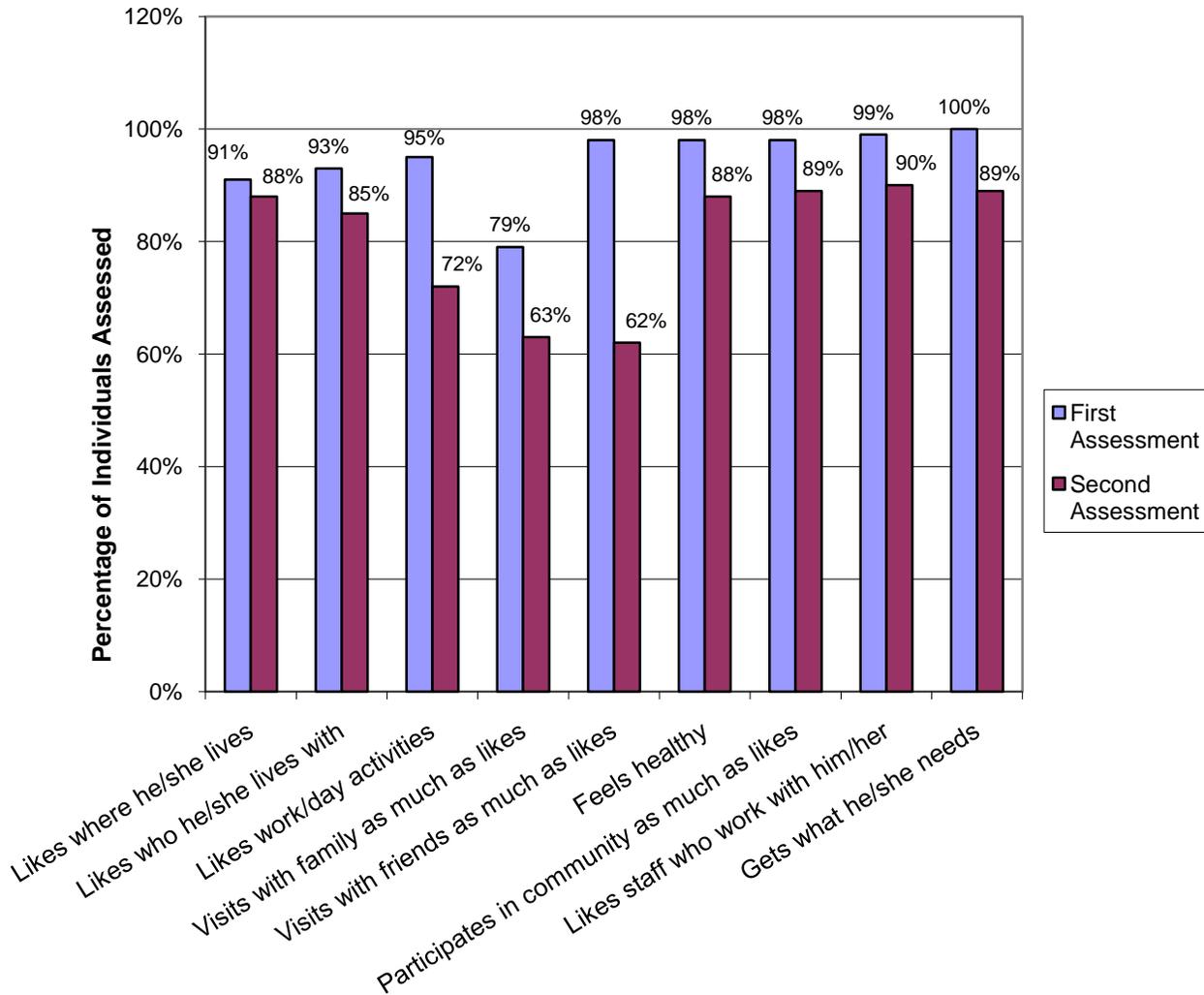
**Comparison of Problems Identified in First and Second Assessments for Partnership in Quality**



Data for type of problem identified was comparable from first to second assessment except for: a) a decrease in out-of-date physical and dental exams comparing first and second assessment periods; b) a slight increase in abuse/neglect allegations; and c) new problems noted comparing first and second periods. Regarding the drop off in out-of-date medical and dental exams, this was largely related to an over-reporting of out-of-date exams in the first assessment which upon further review were found to be inaccurate. (This was discussed in the 2008 report. For a number of cases in the 2008 report, documentation was not readily available to the assessor at the time of the assessment but subsequent investigation confirmed that annual medical and dental exams had occurred.) As previously noted, data indicate problems occurred for a relatively small percentage of persons in each category area; these problems were not evident for the majority of individuals.

**FIGURE 11**

**Comparison of Satisfaction from First and Second Assessments  
for Partnership in Quality**



Satisfaction data continue to indicate that most individuals were satisfied with most life areas. In comparing data from the more recent survey with data from the initial survey, most categories showed a modest percentage drop in satisfaction. Some categories show a more pronounced drop. One explanation is that a number of individuals had changes in life circumstances leading to less satisfaction from the first to second assessment. While possible, this explanation does not seem intuitive to the authors of this report in the context of the actual life circumstances of these persons. Another possible explanation is that individuals reported spuriously high rates of satisfaction in the previous survey; upon examination the data reported in 2008 do appear to be somewhat higher than might be expected, particularly in categories where satisfaction rates are 98% or higher. The previous rates might be affected by a “honeymoon” effect when people first left the Center and moved into new settings; overly positive evaluations are sometimes observed

in the context of extreme novelty. Another possible explanation is that while individuals were initially satisfied with new environments, in general as people become acclimated to life settings and surroundings, they begin to aspire for more and better experiences. Few people are satisfied with all areas of their lives. Some of the above statistics are more accurately interpretable in the context of qualitative data not visible on graphs. For instance most individuals who reported they were not satisfied with their living environment and with whom they lived expressed this because their preference was to live with family, which for various reasons was not an option. Dissatisfaction of some individuals with day/work activities was not unexpected in the context of ongoing difficulty finding personally enriching work activities for some persons. Some persons report drops in satisfaction in areas of day activities and disposable income when they were previously employed on grounds and later had difficulty finding work and earning money in community settings. Dissatisfaction of some persons with frequency of contact with family and friends has been a common finding in other surveys of this nature. These issues, accessing enriching work and social experiences, are issues that continue to require focus for these individuals, for other persons with disabilities in Louisiana, and for persons with disabilities throughout the country. From a services perspective, the identification of areas of dissatisfaction by some individuals brought these issues to the attention of their teams and circles of support, affording them an opportunity to work with these persons to address their concerns. The process of discussing with persons areas of satisfaction and dissatisfaction and taking appropriate actions to address areas of concern must be an ongoing process if supports are to be person-centered and personally enriching.

## **Concluding Discussion**

The Transition and Technical Support Team and Partnership in Quality Project represented attempts on the part of OCDD and GNO to put in place structures that would work collaboratively with individuals, families, and community providers to better ensure that the individuals who left Metropolitan Developmental Center (MDC) would have needed supports and experience successful transitions. The previous sections of this report describe these two transition support initiatives as well as the outcomes for people who left. As noted in the 2008 report, the intent of OCDD was for these supportive structures to monitor and promote the welfare of these individuals for a period of two years. This has been accomplished.

The premise behind the two-year timeframe was that it was surmised that, because transitions can be difficult periods as people adjust to new living circumstances, initially individuals transitioning would benefit from these additional supports. It was also felt that new providers, as they were just getting to know individuals, would benefit from regular and ongoing access to information from Center staff who had a wealth of knowledge about these persons and had been meeting their support needs for many years. For persons who had ongoing professional technical support needs, having the TTST in place to provide technical support would allow

private providers time to develop additional ongoing resources. But it was felt that a reasonable projection was that after a two year period the current providers should have their own wealth of knowledge about individuals and should have had adequate time to identify any additional needed resources, decreasing the need for TTST supports.

As the end of the two-year TTST involvement drew closer, the team undertook a review of the status of all 242 persons who had transitioned. This review included: 1) current status of each person with regard to general welfare and stability; 2) a determination of which persons had current unresolved problems; 3) a determination of which persons had gaps in terms of needed services to assist in resolving these problems (i.e., some individuals might have an ongoing problem but with supports in place to assist with resolution while others might not); 4) identification of the pattern of referral problems for each person over the past two years in terms of predicting potential future problems – what were salient issues, what were re-emerging issues; and 5) identification of the supports and strategies that had been most critical to serving each person over the past two years and most vital in resolving referral problems – that is, based on two years of experiences what emerged as critical ongoing focuses of supports that were important to or important for that person. The TTST utilized their extensive data on each person as well as PIQ data in conducting these reviews.

This review process resulted in the following findings:

- Most individuals who had transitioned from MDC/GNO were stable in current settings and reported satisfaction with most life areas. (In terms of qualitative data, during the review process the TTST discussed many individuals with significant needs who were flourishing and who were having great successes in the community. While individual case data of this nature only tell parts of the story within the context of the overall group data, they continue to add to the reported experiences of other states that with adequate supports in place many residents of large residential facilities, including persons with significant medical and behavior support needs, can live safely and happily in the community.)
- Consistent with the historical needs of these persons, at any given point in time, some percentage of these individuals are experiencing a new or re-emerging problem that requires intensive supports from caregivers and providers. These problems may be medical, nutritional, orthopedic, behavioral, or psychiatric in nature. Other problems relate to meeting ongoing needs important for quality of life – employment needs, social needs, recreational needs, self-advocacy needs, community inclusion needs, etc. The intermittent emergence of new or previously existing problems for these persons in the future is to be expected. Most of these problems have solutions with proper supports in place. Providers need to be prepared for the emergence of these problems.

- While most persons who transitioned were able to have their needs met in the initial transition setting, for some individuals the process of changing providers or settings is necessary until a more appropriate match between person and provider/setting is identified.
- For individuals who transitioned to a different Supports and Service Center, access to professional resources was not a problem. For individuals with medical support needs who transitioned to community settings, in most instances medical resources were able to be located in new community settings. For individuals with allied health needs (e.g., OT, PT, equipment needs, etc.) who transitioned to community settings, these resources were generally able to be located, with the GNO Expanded Resource Center Allied Health section contributing in terms of providing services like physical support recommendations, positioning consultation, equipment design. Location of behavioral and psychiatric supports for persons in community settings was more problematic.

This review also led to a series of final activities, on the part of the TTST following this reporting period, which are described in the final pages of this document.

## **Activities Post June 2009: Conclusion of TTST Supports**

In response to the review described above, the TTST began the process of discontinuation of the automatic tracking and monitoring of each individual. For each individual, the team provided written correspondence and phone or in-person contact with individuals, guardians, and providers notifying them that the TTST would no longer be initiating contacts for the purpose of consultation and technical supports. Individuals and providers were also notified that they had the option of contacting the GNO Expanded Resource Center if additional technical assistance or consultation is needed. (The TTST is a component program of the GNO Expanded Resource Center.)

For each person in a community setting, the written correspondence included a brief review of the major consultation and technical assistance issues and major support needs issues (e.g., person unhappy without a job, wants more social opportunities) as identified by the TTST. The correspondence included recommendations from the TTST as to important support needs that should continue to be a focus in the plans of care of these individuals. Supports that were recommended were supports that significantly assisted individuals once in place, supports that in their absence resulted in the individual experiencing difficulties or major dissatisfaction, and supports that individuals had identified as being important to them. There is a prevention component to these recommendations in that they indicate that continued presence of the supports should mitigate against some future problems and that allowing these supports to lapse would be thought to contribute to greater probabilities of problems emerging. Again the purpose

of the final summaries of critical issues embedded within the correspondence was to document for caregivers and providers supports which should remain a focus and to strongly encourage that these services and supports continue to receive emphasis in plans of care and service provision.

Along with the above, an additional strategy was employed for some persons. In conducting the status review described in previous pages, the TTST identified twenty-one individuals receiving New Opportunities Waiver (NOW) services who had currently unresolved problems or issues, who had unmet needs (e.g., individual continues to be dissatisfied with social opportunities, day activities, employment options, frequency of family contact, etc.), or who had some other support gap. For these individuals, in addition to the TTST correspondence noted above, OCDD proposed that each of these individuals would have their Comprehensive Plan of Care (CPOC) revised using the new Guidelines for Support Planning. This process is outlined in the Guidelines for Planning and is designed to promote more comprehensive, community-integrated, and accountable service plans. (Note: The Guidelines for Planning are available at the following link: <http://www.dhh.louisiana.gov/offices/publications.asp?ID=77&Detail=2633>). With the permission of the individual and caregiver, the final support recommendations by the TTST have been or will be added to the CPOCs in an attempt to address any identified gaps of lack of appropriate emphasis in the plans. Of the twenty-one persons with identified gaps, the TTST has participated in CPOC revision meetings for nine persons and the plans were revised consistent with the new guidelines. CPOC revisions meetings for the remaining persons are pending.

In addition to this extra initiative on behalf of these particular waiver recipients, OCDD is currently working on provisions for intensive support coordination which will allow a small number of these identified persons who have very complex needs and extraordinary case management needs to receive additional assistance and oversight from their support coordinators.

These final actions on the part of the TTST have brought to conclusion the over two-year process inclusive of TTST and PIQ activities. All transitioned individuals will continue to receive current services delivered by their providers and support coordinators. All individuals have the option of contacting the GNO Expanded Resource Center or other OCDD service programs to request assistance in the future. This document represents the final installment of the report on the transition of these 242 extraordinary people and their families, caregivers, and providers who will continue to work with them in their pursuit of their personal goals.

## APPENDIX A: Types of Issues/Problems Referred for TTST Consultation

Note: Tables 4a-4c Extracted from July 2008 Report

<b>TABLE 4a. Types of Issues/Problems Referred for TTST Consultation – Unmet Needs/Personal Goals/Skills Training Issues</b>	
<b>Referral Problems/Categories</b>	<b>Examples within Category</b>
Job/Employment	Needing a job; looking for day program; waiting for LRS services; requiring consultation on how to support someone within job setting
Social Life	Wanting more contact with family or significant others; needing more recreation opportunities; experiencing dating issues
Housing	Needing a living setting with cheaper rent; being dissatisfied with current living arrangement
Financial/Benefits	Needing assistance to obtain SSI money; assisting with confirmation of eligibility for services; requiring consultation on budgeting issues
Community Supports	Needing assistance in obtaining health services in the community; wanting assistance in networking with other community resources
Unfulfilled Wish	Wanting a pet; wanting to live with a parent who was unable to have the son or daughter live with them; desiring to travel
Hygiene	Needing assistance with hygiene; refusing assistance with personal hygiene
Communication	Assisting with training on alternative communication measures

**TABLE 4b. Types of Issues/Problems Referred for TTST Consultation –Behavioral and Psychiatric Support Needs**

Referral Problems/Categories	Examples within Category
Physical Aggression	Hitting others; biting others; spitting on people; throwing objects at others
Self-Injury	Biting self; scratching self; head banging
Property Destruction	Destroying neighbors' property; defacing caregivers' cars
Elopement	Leaving area without notice; whereabouts unknown
Conflict over Caregiver Requests	Being reluctant to accept assistance or advice on personal care; failing to cooperate with medical or dental services
Behavioral Outbursts	Displaying intermittent explosive behaviors
Negative Vocalizations	Cursing; expressing racial slurs directed at people in public
Disrobing	Disrobing in public
Stereotypies	Rocking; hand mouthing; displaying ritualistic behaviors
Law Enforcement	Being arrested; displaying behavior that results in police being called to the scene
Legal Issues	Needing assistance with court appearances subsequent to law enforcement contact; experiencing non-law enforcement related issues such as interdiction or legal advocacy services
Psychiatric Services	Requiring assistance with referrals to mental health services
Placement Stabilization	Experiencing miscellaneous issues resulting in the individual's placement being in jeopardy

**TABLE 4c. Types of Issues/Problems Referred for TTST Consultation – Medical Needs, Physical Support Needs, and Safety**

Referral Problems/Categories	Examples within Category
Medical Complaint	Health issues by history requiring ongoing supports or emergent medical issues requiring attention from medical staff; hypertension; diabetes management; constipation; skin breakdown; dental services; gastrointestinal follow-up; seizure management; hypothyroidism; fractures or other injuries
Positioning	Physical positioning protocols requiring consultation
Swallowing	Dysphasia; at-risk for choking or aspiration requiring ongoing supports and preventive measures
Physical Supports	Assistance with walking, eating, or drinking
Weight Control	Assistance for being underweight as well as overweight
Nutritional Supports	Guidance related to food textures, enteral nutrition, and hydration issues
Adaptive Equipment Needs	Assistance obtaining wheelchair, tub chairs, specialized beds, positioning bars, lifts
Abuse/Neglect	Follow up on reports of abuse or neglect in new settings