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# Residential Enhancement Service Planning Opportunities for New Directions Program (RESPOND): A Program Evaluation

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## Allegheny County Department of Human Services

The Allegheny County Department of Human Services (DHS) is dedicated to meeting the human services needs of county residents, particularly the county's most vulnerable populations, through an extensive range of prevention, early intervention, crises management, and after-care services.

This report was prepared by the Office of Data Analysis, Research and Evaluation (DARE), an office within DHS. DARE supports and publishes research related to the activities of DHS offices including: Aging; Behavioral Health; Children, Youth and Families; Community Services; and, Intellectual Disability.

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## Table of Contents

## Figures

## Tables

## Acronyms

CAFAS – Child and Adolescent Functional Assessment Scale

CCBH – Community Care Behavioral Health

CYF – Office of Children, Youth and Families

DARE – Office of Data Analysis, Research and Evaluation

DHS – Allegheny County Department of Human Services

DSM-IV – Diagnostic and Statistical Manual of Mental Disorders - IV

HCSIS – Home and Community Services Information System

IEP – Individual Education Plan

ISP – Integrated Service Planning Process

MSRRT – Multi-Systems Rapid Response Team

MTT – Mobile Treatment Team

OAS – Overt Aggression Scale

OBH – Office of Behavioral Health

OID – Office of Intellectual Disability

RESPOND – Residential Enhancement Service Planning Opportunities for New Directions Program

TTSR – Training Toward Self-Reliance

UPMC – University of Pittsburgh Medical Center

WPIC – Western Psychiatric Institute and Clinic

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## Executive Summary

### Overview

DHS has a wide variety of services available for children and families to assist them in living safe and productive lives. Some children and young adults face serious barriers to well-being because their lives are complicated by multiple complex issues such as intellectual disabilities, severe emotional disturbances, violent behaviors, autism spectrum disorders and mental illness. DHS approaches complex cases with a "whatever it takes" service delivery process that pulls together natural supports associated with the child and his or her family, as well as representatives from all appropriate systems to determine the best solution for the child.

Two forums for this discussion include the Integrated Service Planning Process (ISP), formerly known as the County Interagency Process, and the Multi-System Rapid Response Team (MSRRT) review. Youth whose needs are not met by the customary service system are first referred to the ISP. If the ISP does not produce a viable resolution, the case is referred to the MSRRT. From here, the team explores every viable option across systems in combination. When the current array of services does not adequately meet the child's needs, the team may recommend that the youth be admitted to the Residential Enhancement Service Planning Opportunities for New Directions Program (RESPOND). RESPOND was developed through a Request for Proposal process initiated by DHS in response to noted gaps in services for youth with intellectual disabilities who were also demonstrating significant behavioral challenges.

RESPOND is an intensive treatment program utilizing two residential providers with highly trained staff, supported with an array of services and the clinical skills and support of a Mobile Treatment Team (MTT). The program is designed to assist youth whose complex needs pose the most difficult challenges. RESPOND operates using a collaborative model that integrates effective clinical treatment with principles of psychiatric rehabilitation, applied behavior analysis and community support programs.

The intensive care and full array of services provided in communities, residential settings, schools and families' homes during involvement with RESPOND is designed to improve the participants' quality of life and provide stability and an understanding of appropriate care and treatment that can be sustained over time, reducing crises and saving treatment costs in the long run. The purpose of this report is to examine if these goals are being attained by measuring the impact RESPOND has on participants and public resources, and to evaluate if this impact is sustained over time.

## Methodology

The findings presented in this report represent three different methods for analysis of programmatic success; these methods include the analysis of outcome and process measures, interviews with natural and professional supports and trends in public costs. Data for the outcome and process measures were collected from the RESPOND program records and supplemented by data from the OID and Home and Community Services Information System (HCSIS). Contact was attempted with all caregivers for youth who completed RESPOND in order to invite them to participate in an interview about their experiences with RESPOND. When caregivers could not be reached, contact was attempted with other natural or professional supports who could speak to the youths' experiences. The final piece of data, related to public costs of care, was pulled from the DHS Data Warehouse, which stores information on the costs of services rendered for the many different program offices administering services to RESPOND consumers. Costs were analyzed from two years prior to admission through two years following discharge from RESPOND.

## Findings

From the launch of RESPOND in March 2003 through August 2010, a total of 30 youth were served by the program. Twenty-six had completed the residential portion of the program, and six of these were still receiving services from the MTT during the transition process from RESPOND residential to the individual's home or other community-based residential option.

*Outcome and Process Measures*

- The data revealed that psychiatric hospitalizations, staffing ratios, and the use of restraints were all positively affected by the program. After entering RESPOND, the treatment and behavioral interventions administered by the RESPOND team allowed the youth to function in a less intensive environment with less oversight, and this continued after discharge from the program. In these environments, youth were also significantly less likely to encounter crisis situations that would result in psychiatric hospitalization or require the use of restraints.

- Youth also made moderate progress on indicators for aggression, functional behaviors and mental health. Progress in these areas varied by the individual, with some youth experiencing little to no change and others demonstrating a substantial improvement.

- No indicator or measure showed a post-enrollment decline in RESPOND youths' performance or progress.

- One noteworthy process measure is the length of stay following youths' designation as discharge-ready. This length of stay was greater than 50 percent of the total time spent in the residential portion of the program for 12 of the 26 youth who completed RESPOND. These time lags have significant implications for program cost and sustainability. On average, RESPOND participants spent 7.9 months in the program after designation as discharge-ready.

*Interviews*

Interviews with caregivers and professionals who worked closely with the youth participating in RESPOND helped to clarify program strengths and areas of improvement from the perspective of the families and the professional support personnel. Interviews were completed with eight caregivers and eight professional support staff. These 16 interviews spoke to the experiences of 13 unique youth – half of the population who had completed the program. The interviews revealed a spectrum of experiences and opinions, ranging from positive to negative.

- Families repeatedly identified the following items as strengths of the program: the coordination of services; communication with the RESPOND team; the expertise and impact of the MTT; their child's development and maintenance of coping skills; and the overall impact the program made on their lives.

- Two primary areas for improvement were identified by multiple respondents. The first was to better prepare adolescent youth for transition into the adult system of care where they would need to be more independent and possess better self-regulation skills. The other identified concern was the competency and appropriateness of some of the residential staff caring for the youth, both during RESPOND and following discharge.

- The transition out of RESPOND was identified by many as a challenging and critical point in the process. Some youth had great experiences (exceeding the expectations of their families), while others did not and struggled through the transition process. The interviews indicated that the potential cause for these differences was communication. Families experiencing a great transition commented on how well everyone communicated and collaborated throughout the process. Difficulty during transition often seemed to be tied to some form of communication breakdown.

- Regardless of individual perspectives on specific aspects of the programs, all participants felt that the program as a whole made a positive difference in the lives of these youth and helped caregivers to better understand and work with the system of services available to their child.

*Cost Analysis*

Public costs for each individual vary over time – climbing just prior to entry into RESPOND while youth were in crisis and frequently utilized inpatient psychiatric hospitalizations. Costs peaked during RESPOND and then fell sharply after discharge. The average daily cost per consumer following discharge from RESPOND was substantially lower than prior to RESPOND. The average difference amounted to $103.40 per day.

Trending of categorical spending revealed that the composition of services generating costs changes markedly between the two periods of time. Prior to RESPOND, nearly all expenses are for intervention services – in fact, 73 percent of all spending is for psychiatric hospitalizations. Following RESPOND, costs for prevention services surpass intervention services, and inpatient hospitalizations are responsible for only 17 percent of costs. In the two years following RESPOND, intervention services are kept lower than during any other period, maintaining a decrease in total costs.

## Conclusion

Overall, the combination of outcome and process data, interviews, and cost data illustrate a coordinated team of experts who communicate well with the family and other stakeholders to tackle the challenges that youth with complex needs experience on a daily basis. This collaborative effort results in treatment that is more effective than any received by these youth in the past, and the impact is sustained beyond program discharge. The youth enter more stable living environments, require fewer and less costly services and experience fewer crises. Service utilization is concentrated in preventive services. Caregivers and treatment providers better understand how to work with the youth, improving the youths' quality of life, increasing safety and decreasing caregiver stress.

## Background

DHS has a wide variety of services available for children and families to assist them in living safe and productive lives. Some children and young adults face serious barriers to well-being because their lives are complicated by multiple complex issues such as intellectual disabilities, severe emotional disturbances, autism spectrum disorders, violent behaviors and mental illness. DHS approaches complex cases with a "whatever it takes" service delivery process that pulls together natural supports associated with the child and his or her family, as well as representatives from all appropriate systems, to determine the best solution for the child.

Two forums for this discussion include the ISP and the MSRRT review. Youth whose needs are not met by the customary service system are first referred to the ISP. If the ISP does not produce a viable resolution, the case is referred to the MSRRT. From here, the team explores every viable option across systems in combination. When the current array of services does not adequately meet the child's needs, the team may recommend that the youth be admitted to RESPOND.

### Integrated Service Planning Process (ISP)

DHS established the ISP, formally known as the County Interagency Review Process, in 1997. The ISP provides a method to develop, implement and monitor a comprehensive plan that includes a full continuum of services and tangible assistance, when needed, to support a child or youth who is involved in more than one system, when normal and customary service delivery falls significantly short of goals.

Each child and his/her family is joined in the planning process by representatives from the DHS Executive Office, OBH, OID, CYF, Child and Adolescent Crisis Team Intervention Services from the Western Psychiatric Institute and Clinic (WPIC) of the University of Pittsburgh Medical Center (UPMC), service coordinators, community providers and other natural supports that may be identified by the family. To avoid confusion and duplication of services, the ISP team plans with families and focuses on the strengths of the child and family to coordinate services.

This process results in the creation of a Joint Service Agreement to coordinate the implementation of the jointly created plan. The plan includes goals for overall care, health, educational, and vocational planning, as well as for developing and maintaining a support system. To ensure that the plan is implemented after the meeting, an Interagency Liaison conducts follow-up communication with families and participants.

Consumers are referred to the ISP for a number of reasons, most commonly for transition planning or to review services currently in place.

## Multi-System Rapid Response Team (MSRRT)

If the ISP process does not produce a viable resolution, the case is referred to the MSRRT. Started in October 2001, the MSRRT is an administrative review offered to assist in meeting the needs of children or youth with complex needs. These cases frequently require solutions that are not readily available within the system of care; the complexity of the possible solution will require multi-system intervention. Most children referred to MSRRT have had multiple placements without success, and/or their situation may be complicated by a physical health condition. Their behavior renders any medical or specialized intervention difficult and sometimes even impossible.

The cross-systems MSRRT regularly brings representatives from each child-serving system together to identify trends and gaps in services and to carry out proactive planning and tracking. In addition, the MSRRT gathers for urgent meetings to review the circumstances and do "responsive planning" for a child or youth who is at imminent risk of losing his or her placement, for whom all viable options and appropriate resources have been explored, or for whom special services are needed that do not currently exist in the system[1].

MSRRT members strategically develop viable (short- and long-term) plans that maximize the potential of each child or youth referred to them while minimizing barriers to service and treatment and enhancing resources available to service providers. In this way, the MSRRT ensures that supports and services are provided to individuals in the most integrated setting and in the most effective and efficient manner.

One potential outcome of a review by the MSRRT is referral to the RESPOND program.

## Residential Enhancement Service Planning Opportunities for New Directions Program (RESPOND)

*Overview*

RESPOND was established in 2003, and is an intensive residential treatment program designed to assist youth whose complex needs pose the most difficult challenges[2]. Individuals often have a history of one or more challenging behaviors,

1 While similar services may exist, providers are not able to offer the combination and intensity of services needed for these youth. Since they do not have the capacity to meet the complex needs of the child, providers will not initially accept the child for service.

2 For the personal stories of two youth who participated in RESPOND, see the DHS: Making an Impact piece published about RESPOND. This document is available online at http://www.alleghenycounty.us/dhs/impact.aspx.

## Background

such as severe mood disorders; inappropriate sexual behaviors; severe aggressive, assaultive or self-injurious behavior; limited cognitive functioning; and/or physical health needs. The needs of this group of children and youth exceed the staffing ratios and behavioral intervention capacities of specialized Residential Treatment Facilities.

RESPOND was developed through a Request for Proposal process initiated by DHS in response to noted gaps in services for youth with intellectual disabilities, who were demonstrating significant behavioral challenges. It was initially established for children and adolescents with intellectual disabilities, autism spectrum disorders and complex needs, and was later expanded to include youths without intellectual disabilities and with significant involvement with juvenile probation.

Youth are provided with whatever it takes to attain a long-term quality life with the least supervision possible and minimal support that is matched and appropriate to the youths' abilities. RESPOND operates using a collaborative model that integrates effective clinical treatment with principles of psychiatric rehabilitation, applied behavior analysis, and community support programs across residential, school, family, and community settings. The residential staff in each community house are highly trained individuals with experience working with children and youth with complex needs, and are trained, coached and supported by a shared MTT. These two groups of staff members make up the RESPOND team.

*Program Design*

Program capacity is limited to six youth at any given time. There are three residential settings, and each RESPOND residence houses two children. The residences are staffed 24/7 by up to six professionals highly trained in behavioral intervention. The staffing patterns fluctuate based on the need and progress of the individual, with staff–to-child ratios ranging from 4:1 to 1:1. Over time, staffing is reduced as the youth achieves success with less support, and the team engages in transition planning prior to discharging the youth to a less restrictive setting.

In addition to the residential staff, each residence is supported by the MTT. Team members include a child clinical psychologist with specialization in applied behavior analysis, child and adolescent psychiatrist, psychiatric nurse, behavior analyst, social worker and community-based clinician who have a range of clinical expertise in intellectual disabilities and child psychopathology; both program specialists and program managers from the residential providers work with the team as well. The MTT travels from residence to residence on scheduled visits and in response to urgent needs. Their combined expertise integrates behavioral health supports with physical health supports to improve outcomes. In addition, the MTT

## Background

and residential staff support youth in the school settings selected as most appropriate by the Individual Education Planning (IEP) process. This includes providing staffing support and joint consultation between the MTT and school staff.

When a child is accepted into RESPOND following review by the MSRRT, the RESPOND team gets to know the child and his/her life history well by going to the child's home and school and interviewing everyone involved. The team also takes an in-depth physical and mental health history. Team members want to know what drives the child, to identify his/her strengths, and to determine existing barriers to living a full life. This evaluation is followed by integrated meetings to design an Individual Service Plan. All interested parties are brought to the table to discuss options, but decisions are made by the child and his/her family.

Through the entire process, the original integrated planning team supports the work of RESPOND and ensures that the family's voice and choices are being honored. The team regularly reviews each child's progress and ensures access to resources to facilitate transitions. The formal service plan is updated every six months, and the RESPOND team comes together with the family and other stakeholders at monthly interagency meetings to share progress and discuss goals and plans moving forward. The methods by which the goals identified in the service plan will be carried out are specified in the child's treatment plan. The treatment plan is fluid, with frequent, ongoing changes made as a refined understanding of the child is achieved, and as old problems are addressed and new problems arise. The plan includes strategies to address mental health, physical health (nutrition, dental, etc.), educational and vocational needs, and daily living skills.

When many of the goals have been achieved and the child is ready for discharge, the planning team starts the discharge planning process by identifying the next appropriate level of treatment. Discharge may be to a family setting or to a residential facility. The physical move is preceded by visits that allow the youth to adjust to his/her new environment gradually. RESPOND residential staff will accompany the child to his/her new setting and help train the new staff or caregivers by modeling and coaching them on the interventions found to be effective with the youth. In addition to working with new caregivers, the team identifies a new treatment team, and the MTT shares behavioral techniques they developed for the child. At discharge, the MTT and the new treatment team work together for a transitional period that lasts about one to three months. When the child is comfortable with the new team, the MTT phases out and the new treatment team takes over.

## Background

*RESPOND Partners*

RESPOND was designed by WPIC of UPMC and the MTT is comprised of WPIC staff. This program is multi-system funded and regulated through the Community Care Behavioral Health (CCBH) and OBH, OID and CYF.

The three contracted providers for residential care over the life of the program were the Laurel Highlands Foundation, Familylinks, and Training Toward Self-Reliance (TTSR). The Laurel Highlands Foundation currently maintains four of the six beds, and Familylinks is responsible for the other two. The children and adolescents have been served in multiple school placements ranging from specialized programs in neighborhood schools, to private approved schools specializing in specific child needs, to partial hospitalization programs.

## Methodology

### Sources of Data

The evaluation team collected program data from multiple sources. The RESPOND MTT provided the data presented and discussed in the Outcome and Process Measures section. This included data on evidence-based functional scales and assessments (Child and Adolescent Functional Assessment Scale [CAFAS], Devereux, and Vineland), aggression, hospitalizations, medications and survey results.

Incident reports, restraint data and average daily residential rates were provided by OID.

Staff from DHS's Executive Office and OID worked with the evaluation team to identify and update contact information for caregivers and other natural and professional supports of the youth, in order to be able to make contact for interviews developed by DHS separately from the surveys used by the MTT and developed at WPIC/UPMC. All anecdotal findings discussed in the report come from the DHS interviews with caregivers and professional staff (outside of the RESPOND team) who worked with the youth.

All data related to the costs and unit-hours of services delivered to RESPOND participants and funded through DHS programs is integrated into the DHS Data Warehouse. Service and cost information dating back to fiscal year 2004-2005 was pulled for mental health, drug and alcohol, intellectual disability, and children, youth, and family services.

### Interview Design and Expectations

To capture the perspectives of family members and other natural supports of program participants, the evaluation team conducted 16 interviews. The interview tools were designed to elicit information that would increase our understanding of the impact of RESPOND on its participants' behaviors, living skills, lifestyle, and service needs, as well as to examine the experiences of families as they worked with the RESPOND team. The tool was reviewed by RESPOND team staff as well as representatives from the Executive Office, OBH, OID, and a family advocate.

Offers to participate in interviews were extended to all identified family members active in the youths' lives. At the time interviewing began, 26 youth had completed RESPOND. Since the population was small, no youth were sampled out. Families were not contacted for some youth because active family members could not be identified, contact information was out of date and new information could not be found, or parental rights had been terminated.

## Methodology

In order to increase the response rate among available family members, interviews were confidential and conducted by phone or in person, depending on the respondent's preference. Two DARE staff members were present at each interview: one individual conducted the interview while the second took notes.

Supports coordinators and caseworkers for the youth were contacted prior to family members in order to introduce the project, confirm familial involvement, and update contact information. Other natural supports were also identified at this stage. Advance letters were then sent to all primary caregivers, introducing the project and providing contact information for the evaluation team if they had questions or wanted to schedule the interview. Follow up phone calls were made the following week, and continued to be made until contact was established, or until multiple calls were made and voicemails went unreturned.

*Response Rate*

DHS DARE staff made contact with family members for ten of the youth. The primary reasons for lack of contact with the other youths' families included incomplete information, disconnected phone numbers and unreturned calls. Of the ten contacted, eight participated, and six interviews were fully completed.

For youth for whom no family members were interviewed, other natural supports or professionals who knew the youth well were sought out. This included school personnel, residential staff, and KidsVoice Case Advocacy Specialists. Staff members who were formally on the RESPOND team were excluded from the list of potential contacts. In addition to the eight family members interviewed, an additional eight professionals spoke about youths' experiences in the program.

A total of 13 unique youth were represented by the interviews with family members and professionals. This represents half of the population who completed the RESPOND residential program.

### Cost Analysis

In DHS, data of services rendered by DHS providers and many other public entities is housed in a centralized data warehouse. The Data Warehouse was created in 1999 and contains information on all consumers served by DHS. Since this is an integrated database, cost information for this report was pulled from the Data Warehouse for each RESPOND consumer. Some consumers did not use public systems in the earlier stages of receiving psychiatric and psychological services. Any services that RESPOND consumers received that were paid for through private insurance or out-of-pocket expenditures are not included in this analysis. In addition, some participants resided outside of Allegheny County for some

## Methodology

period of time, and the costs of services received in these other localities are not included here. This data represents the public cost of care, as administered through DHS and its providers.

The cohort studied in this cost analysis is composed of all consumers entering RESPOND from the beginning of the program in March 2003 through September 2010. During that time period, 30 consumers were admitted into RESPOND.

The cost study covers the period extending from two years prior to admission into the RESPOND residential unit until two years following discharge from the RESPOND MTT. The RESPOND time period includes involvement with the MTT after discharge from the residential unit because services are still being administered at a high level by the RESPOND team during the transition period. The two-year timeframes before program entry and following program discharge are used to capture estimates of services that are incurred both close to the consumers' time in RESPOND and over a period of time long enough to capture long-term trends in care.

Not all youth in this cohort have been out of the RESPOND program for two full years. These individuals are excluded from the analyses examining changes in the public cost of care for RESPOND participants after discharge from the program. Their data is included in descriptive statistics and analyses related to costs prior to and during RESPOND.

## Limitations

Limitations to the analysis presented in each section of the report are outlined below. One limitation that bridges the different sections is the absence of a comparison group. The individuals admitted into the RESPOND program exhibit very challenging behaviors. Their needs, and the services provided to meet those needs, are unique; there is no adequate group of youth for whom we have data to serve as a control for those receiving services through RESPOND. As a result, for the purposes of this report, progress attributed to involvement with RESPOND must be analyzed through a pre- to post-RESPOND lens in the outcome and cost analyses.

### Outcome and Process Measures

A significant amount of daily progress data is collected during the program by the RESPOND team, and the intent of the data is to provide functional behavior assessment, inform treatment, and help all stakeholders better understand the behavior of the children and the impact of the interventions the RESPOND team is making. While data plays a critical role in effective treatment and program operations, it provides little analytical power in the attempt to evaluate the impact of the RESPOND program on the youth who are participating. Most program outcomes by which the effectiveness of the program could be evaluated are not captured by such data. For example, progress on key goals for each child is not tracked in a manner that would allow it to be quantified or evaluated for program evaluation purposes.

Consistently, the largest barrier to evaluating outcome data is the unavailability of related data sets from the pre-RESPOND and post-RESPOND settings. This applies to variables such as aggression, restraints, hospitalizations, and other incidents. During involvement with RESPOND, treatment changes may have varied impacts on behavior, so fluctuations can be expected. Without data on these indicators prior to program entry and following discharge, it is difficult to gauge empirically how RESPOND impacts an individual's aggression, behavior, and stability.

A few data elements that are collected could be used to evaluate program impact if the data was more robust. Three functional scales and assessments are administered to youth when they enter and exit RESPOND. However, results from these assessments at both the points of entry and exit are available for very few youth because the assessments were not always conducted during the same timeframes. This inconsistency decreases the utility of the data.

## Limitations

One more factor contributing to the varying degree of data availability is that some data is recorded in compliance with funding requirements. When these requirements change, data may be recorded and tracked differently than in previous years, disrupting the availability or consistency of the data. For example, staffing ratios were only available from 2004 through 2008.

### Interviews

The primary limitation to the interview results is the low representation of youth who had limited family involvement during the program. It was very difficult to identify natural supports or professional contacts to speak to about youth with few or no family ties. If the experiences of these youth varied significantly from those with family involvement, they may not be adequately represented in these results.

### Cost Analysis

In addition to the absence of a comparison group, the second major limitation to the cost analysis is the unavailability of data prior to and following RESPOND participation. While costs borne by Allegheny County providers are available in these time periods, cost data is not available if a child lives outside of the area. Additionally, if a participant lives at home or has some costs covered by private insurance, these costs are not included in the evaluation. While the evaluation may capture the cost of care to Allegheny County, it would be ideal to be able to capture all costs over time so that the true impact of the program on total costs of care could be better understood.

Additionally, the cost data as recorded in JD Edwards (accounting software) is difficult to interpret relative to payment for specific services rendered. For this reason, costs and service units rendered are only analyzed at very high levels, either by looking at total costs or large groupings of service categories.

## Population Served by RESPOND

At the time of this report, a total of 30 youth were served by the RESPOND program. Twenty-six had completed the residential portion of the program, and six of these were still receiving services from the MTT during the transition process. The charts and figures in this section provide a basic overview of the population of youth served by RESPOND, including information about their demographics, system involvement, diagnoses and living arrangements.

### Demographics

Table A lists the number of youth in RESPOND by race and gender. Figure 1 displays the age distribution of youth at the time they entered the RESPOND program. Just over half of the program participants are African American, and 57 percent are male. The majority of youth served by the program were adolescents, but one-fifth were age eight or younger at the time of entry.

| | Count |
|---|---|
| **Race** | |
| African American | 16 |
| White | 11 |
| Other | 3 |
| **Gender** | |
| Female | 13 |
| Male | 17 |

*Table A: Demographics of RESPOND participants*

## Population Served by RESPOND

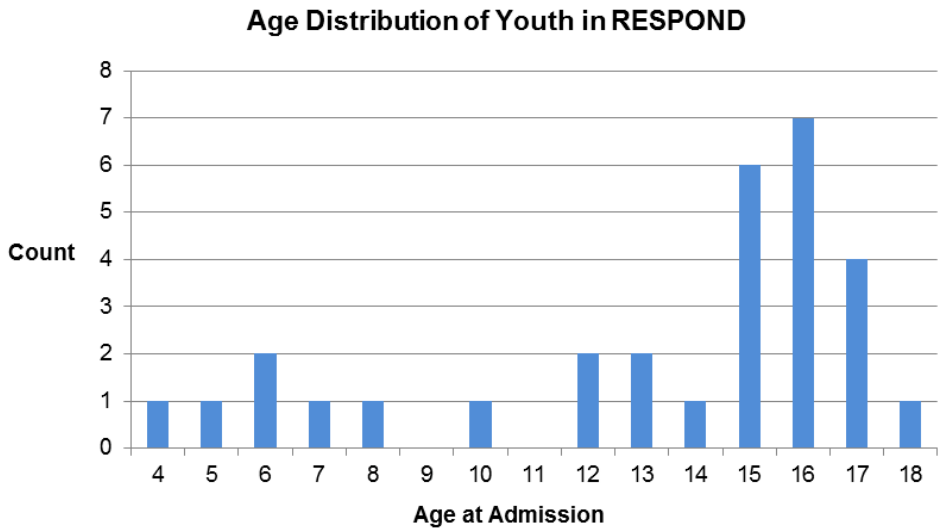


*Figure 1: Age Distribution of Youth in RESPOND*

### System Involvement and Diagnoses

Each youth admitted into the RESPOND program was involved in at least two systems, and many were involved in more than two[3]. Twenty-six of the 30 youth have an intellectual disability and had received services from OID prior to entering RESPOND. Levels of intellectual disability ranged from severe to borderline intellectual functioning to no intellectual disability[4].

All 30 youth faced mental health challenges, so involvement with OBH was also prevalent. At admission, Axis I (mental health) diagnoses from the Diagnostic and Statistical Manual of Mental Disorders – IV (DSM-IV) included anywhere from three to six separate diagnoses for each youth. The youth have received diagnoses such as Autistic Disorder, Pervasive Developmental Disorder, Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder, Intermittent Explosive Disorder, Disruptive Behavior Disorder, Bipolar Disorder, Mood Disorder, Conduct Disorder, Impulse Control Disorder, Psychotic Disorder, and Schizoaffective Disorder. The diagnoses show no trend other than being very diverse and very complex. Aggressive tendencies are the one common theme[5]. Based on

3 "Systems" are considered to be large sets of services housed within an office of DHS, or another government agency. Within each system, an individual may access multiple services, possibly from more than one provider. Examples of systems include intellectual disability services, mental health services, child welfare services, juvenile probation, etc

4 RESPOND Annual Report. July 2009. Western Psychiatric Institute and Clinic. University of Pittsburgh Medical Center.

5 RESPOND Annual Report. July 2009. Western Psychiatric Institute and Clinic. University of Pittsburgh Medical Center.

youth progress in the program, the youths' DSM-IV diagnoses were simplified and/or clarified by discharge[6].

A third DHS office with which many RESPOND youth are involved is CYF. Families may receive in-home services through CYF that are designed to strengthen family functioning. If it is determined that a child's health or safety is in danger, an out-of-home placement will be made until the child can safely return to the family. In some cases, this placement may occur because the family is unable to meet the complicated needs of the child, or the child is a danger to him/herself. Fifteen of the 30 youth experienced an out-of-home placement prior to their entry into RESPOND.

Finally, eight youth were also involved with the juvenile justice system prior to entry, with three having experienced a delinquency placement.

## Residence Prior to RESPOND

*Court-Mandated Placement Activity*

If a child enters an out-of-home setting in the child welfare or juvenile probation systems, finding an appropriate and stable placement may be particularly difficult if that child has an intellectual disability and exhibits challenging behaviors. These youth are more likely to experience multiple placements than other youth who do not have these challenges. Multiple placements result in familial and social bonds being repeatedly disrupted, and this instability can have a negative impact on youths' education and development[7].

Table B displays the placement activity of RESPOND participants experiencing out-of-home placements through CYF. These numbers reflect the number of continuous periods of time that each child is in out-of-home care, from entry to exit. Each entry into placement may entail moves between placement settings. Fifteen youth in the RESPOND program experienced an out-of-home placement, and eleven of them experienced more than one entry into placement (73 percent). Three of these 15 youth also experienced at least one placement with juvenile probation.

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6 RESPOND Annual Report. July 2009. Western Psychiatric Institute and Clinic. University of Pittsburgh Medical Center.

7 Wulczyn, F., Chen, L., &Hislop, K.B. (2007) Foster care dynamics 2000–2005: A report from the Multistate Foster Care Data Archive. Chicago: Chapin Hall Center for Children at the University of Chicago.

Sigrid, James, et al. "Predictors of Outpatient Mental Health Service Use—The Role of Foster Care Placement Change." Mental Health Services Research. Vol 6, No 3. September 2004. pp. 127-141. Available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1550708/.

| Number of Entries into Placement | Number of Youth |
|---|---|
| 1 | 4 |
| 2-3 | 5 |
| 4-5 | 3 |
| 6+ | 3 |

*Table B: CYF Placement Activity*

*Residential Placements*

Some youth were in a residential placement for treatment purposes prior to RESPOND. There was no court activity for these youth through the child welfare or juvenile justice system. Nevertheless, youth experienced difficulty finding a suitable residential living facility because the behaviors they exhibited were so challenging. Even though staff in these facilities was trained to work with youth facing similar challenges, the compounded effects of their intellectual, mental health and behavioral challenges resulted in their needs exceeding the capacity of the residential facilities.

*Residential Setting at Admission*

Table C lists the residential locations of youth at the time of their referral to the program. As an indication that these youth were in crisis, twelve were in inpatient psychiatric hospitalizations, eleven were home with their families and the remaining seven were in another form of out-of-home placement.

| Location at Referral | Number of Youth |
|---|---|
| Psychiatric Inpatient | 12 |
| Home with Family | 11 |
| OID Residential | 4 |
| Delinquency Placement | 2 |
| Foster Care | 1 |

*Table C: Residential Location at the Time of Referral to RESPOND*

## Outcome & Process Measures

RESPOND program staff record and maintain data on several behavioral indicators, outcomes, and process measures. These include standardized functional scales and assessments, levels of aggression, medications, hospitalizations, restraints and other incidents and discharge destinations. In addition to the data tracked by program staff, WPIC-designed surveys are regularly sent to the families of RESPOND participants to collect feedback.

Much of this information is used by the RESPOND team for functional behavior assessment and to inform treatment and behavioral interventions. The information is used here for program evaluation purposes to examine participants' progress from the point of entry into RESPOND to discharge. Since these are two different goals, some of the information collected was not adaptable to this evaluation. Also, changes in program design and reporting requirements for funding have resulted in changes in the way that some data are recorded. For this reason, data on some of the indicators examined here are not available for all program participants. The discussion for each indicator or outcome measure indicates the number of youth for which the relevant data was available.

### Standardized Functional Scales and Assessments

Data are available for RESPOND participants on three different types of assessments, each measuring a different category of health or development. Each assessment is structured so that the measures are age-appropriate.

- The CAFAS[8] measures functional impairment across eight domains. The domains include school/work role performance, home role performance, community role performance, behavior toward others, moods/emotion, self-harmful behavior, substance use and thinking.
- The Vineland Adaptive Behavior Scales[9] measure the development of skills including communication, daily living skills, socialization and motor skills. This scale is based on the population at large. The population average is 100, and scores below 70 are considered Low at greater than two standard deviations away from the average.

8 Hodges, K. (2000). Child and Adolescent Functional Assessment Scale. Functional Assessment Systems, 2140 Old Earhart Road, Ann Arbor, MI. fas@fasoutcomes.com.

9 Sparrow, S.S., Cicchetti, D.V., & Balla, D.A. (2005). Vineland Adaptive Behavior Scales, Second Edition. Circles Pine, MN: AGS Publishing.

## Outcome & Process Measures

- The Devereux Scales of Mental Disorders[10] gauge mental illness. The scales are based on a sample of consumers of mental health services, not the population at large. Individuals with very elevated scores (above 70) on this scale are most likely in a hospital setting.

The only measure for which data are available for all RESPOND participants is the CAFAS. The pre- and post-scores on the scale are derived one month pre-admission and one month post-residential discharge. Scores can range from 0 to 240, with higher scores representing greater levels of functional impairment. Pre-admission, 15 of the 25 youth (60 percent) scored 140 or higher. Scores in this range indicate that the youth "likely needs intensive treatment, the form of which could be shaped by the presence of risk factors and the resources available within the family and the community"[11]. The remaining ten youth scored between 100 and 130. These scores indicate that the youth "likely needs care which is more intensive than outpatient and/or which includes multiple sources of supportive care"[12].

Figure 2 charts the CAFAS scores for all participants, including the net change in score from program entry to discharge. Scores improved for 22 of the 25 youth (88 percent), remained the same for two, and was not available for one youth who was in the discharge process. Post-discharge, only six youth scored 140 or above, and sixteen scored below 100.

The total CAFAS score for each person is comprised of scores in eight different domains. The four domains with which most RESPOND participants struggle include school role performance, home role performance, behavior toward others, and moods/emotions. Improvement occurred across each of these domains, with the most significant gains occurring in behavior toward others and moods/emotions.

At admission, less than half of the youth struggled in the remaining four domains (community role performance, self-harmful behavior, substance abuse, and thinking). For these youth, there was significant improvement in these domains as well. The improvements are illustrated more clearly in figures demonstrating the changes in individual scores in each domain. These figures are available in Appendix A: Individual CAFAS Scores by Domain.

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10 Naglieri, J. A., LeBuffe, P. A., & Pfeiffer, S. I. (1994). Devereux Scales of Mental Disorders. San Antonio: The Psychological Corporation.

11 Hodges, K. (2000). Child and Adolescent Functional Assessment Scale. Functional Assessment Systems, 2140 Old Earhart Road, Ann Arbor, MI. fas@fasoutcomes.com.

12 Hodges, K. (2000). Child and Adolescent Functional Assessment Scale. Functional Assessment Systems, 2140 Old Earhart Road, Ann Arbor, MI. fas@fasoutcomes.com.

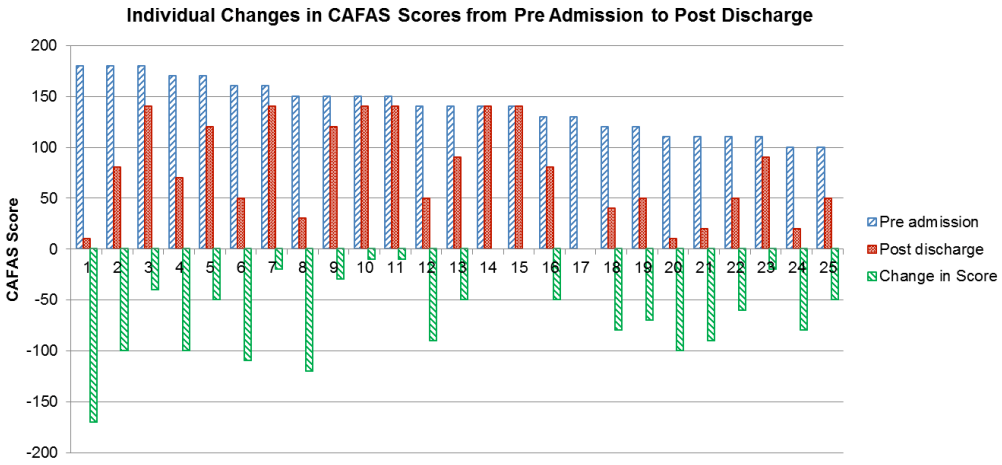



*Figure 2: Improvement in CAFAS Scores, by Individual*

At least one Vineland Adaptive Behavior Scale score is available for 21 youth. Scoring on this scale is opposite that of the CAFAS in that higher scores indicate higher levels of functioning, whereas the CAFAS measures impairment. On the Vineland, most youth scored below 70, placing them in the Low range. The Vineland is standardized by the population at large and measures daily living skills. Given the challenges faced by this group of youth, scores in this range are to be expected. Of the 21 consumers with scores, only six scored over 70 at some point. For the remaining 15 youth, high scores ranged from 20 to 62. Unlike the CAFAS, Vineland scores were not collected regularly at admission and discharge, so it is challenging to make consistent comparisons. At the time of this study, both admission and discharge scores were only available for six youth. Of these six, three made positive improvements. Across scores for all 21 youth, even when improvements were made, they were minimal, and most youth remained below the 70 point threshold.

Scores for the Devereux Scales of Mental Disorders are also available for a limited number of youth. Higher scores on this scale indicate greater levels of distress. Of the 21 youth with at least one score, both admission and discharge scores are available for only eight. Table D displays the number of youth with admission and discharge scores in each category, ranging from Normal to Very Elevated. While only eight youth are included in this data, there is a marked shift in scores as five are in the Elevated or Very Elevated categories at admission, and only one is Elevated at discharge. Thirteen of the total 21 youth had a recorded score in the Elevated or Very Elevated ranges at some point, so the high levels of mental illness are not limited to this group of eight for whom admission and discharge scores are available.

| Score range | Admission | Discharge |
|---|---|---|
| Very Elevated | 2 | 0 |
| Elevated | 3 | 1 |
| Borderline | 1 | 2 |
| Average | 2 | 5 |

*Table D: Devereux Score Distribution at Admission and Discharge*

Overall, the scores on the three functional scales and assessments do indicate improvement in mental health-related symptoms for participants in the RESPOND program. Testing for statistical significance between the admission and discharge scores is not pursued here due to low sample sizes.

## Program Outcome and Process Measures

*Staffing Ratios*

Many youth enter RESPOND when they present behaviors so challenging that their caregivers are no longer able to care for them safely, or the mainstream service system is not able to meet their needs. For this reason, youth usually require very high staffing ratios when first entering the RESPOND program. Data on staffing ratios at program entry were available from July 2004 through August 2008, and they are displayed in Table E[13].

Of the 21 youth entering during this time period, 13 (62 percent) started the program with a 3:1 staffing ratio, and most of the remaining youth entered with a 2:1 staffing ratio. Only one required a 4:1 staffing ratio. As a rule, progress must be made on this measure for all youth because youth are only discharged from RESPOND when they are in, or ready to enter, a residential setting with a maximum staffing ratio of 1:1. Program design does not allow youth to live in less than a 1:1 setting prior to discharge from the program.

| Staffing Ratio | Number of Youth |
|---|---|
| 2:1 | 7 |
| 3:1 | 13 |
| 4:1 | 1 |

*Table E: Staffing Ratio at Entry, July 2004-August 2008*

13 Staffing ratios are only available for this time frame because they were recorded for funding requirements. When funding methods changed, the data was no longer systematically recorded and available for analysis.

## Outcome & Process Measures

*Aggression*

Youth in RESPOND exhibit different types of aggression. The aggression may be verbal, physical toward others, physical toward themselves, or physical against objects. The number and type of aggressive incidents are tracked very carefully by RESPOND staff at all hours of the day, using the Overt Aggression Scale[14] (OAS). The OAS requires staff to record the type of aggression exhibited, who it is directed towards, when it occurs, the duration, and which intervention is used to address the aggression. This data is scored, providing numeric values for the number of 15-minute increments per day during which an aggressive incident occurred.

This information is used to better understand the patterns of each individual's behavior. These patterns help staff members identify what may be causing aggressive behavior and how their interventions, such as changes in medication or behavioral interventions, impact youth.

OAS data were not collected from the outset of RESPOND, so data are not available for all participants. Figure 3 displays the average monthly OAS scores for youth with at least twelve months' worth of data. Averages are provided for each youth's first five months and last five months. These time frames are utilized to capture the level of aggression each youth exhibits during program entry and exit. Aggression scores throughout the duration of the program are not reported because these levels of aggression were expectedly unstable as youth underwent medication modifications and other behavioral interventions.

Overall, aggression levels were significantly lower right before youth left RESPOND than when youth entered. Only two of the thirteen youth for whom data were available experienced higher levels of aggression in the last five months than the first five months. The average aggressive scores decreased by over 50 percent for eight of the thirteen youth.

14 Yudofsky SC, Silver JM, Jackson W, et al: The Overt Aggression Scale for the objective rating of verbal and physical aggression. Am J Psychiatry 1986; 143:35-39.

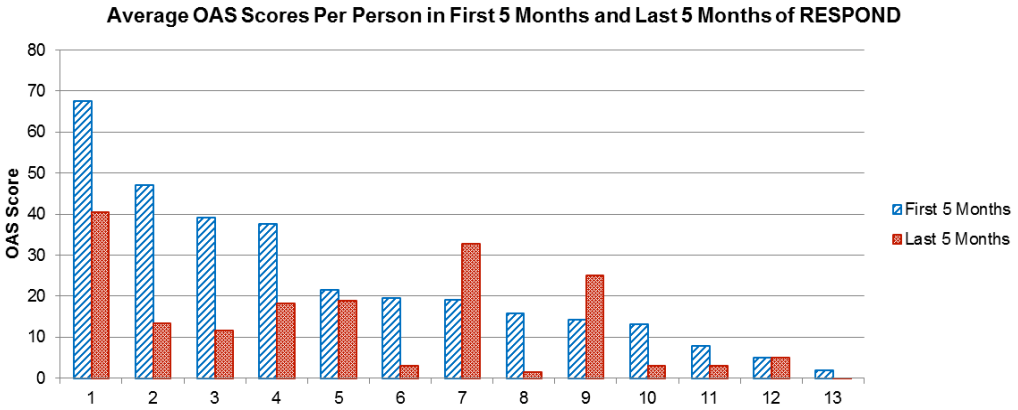



*Figure 3: Average Aggression Scores during First 5 Months and Last 5 Months of RESPOND*

*Incidents*

Incident reports are records of all events that are not part of routine medical care[15]. All providers of intellectual disability services and supports must enter this data into HCSIS, Pennsylvania's data system designed to report incidents that occur while a child is receiving services. Each entity reports certain incidents, collects information about those incidents, and takes action based on those reports. Incidents include but are not limited to law enforcement activity, abuse, psychiatric hospitalizations, emergency room visits, medication errors, and use of restraints. The primary goal of an incident management system is to ensure that when an incident occurs, the response is appropriate and adequate to protect the health, safety and rights of the individual[16].

Since the content of the incident reports has the potential to serve as an outcome measure – changes in the frequencies and types of incidents – they were pulled from HCSIS for all RESPOND participants, dating back to the year 2000. Reports were limited to this timeframe because HCSIS only replaced the paper-based incident reporting in 2000. These reports were aggregated and analyzed for any trends related to care – comparing incident types and frequencies prior to, during, and following RESPOND.

The analysis revealed that the incident reports were in an insufficient tool for evaluation because the data did not accurately reflect the experiences of youth in the program. All incidents were meticulously recorded during the RESPOND

15 Richards, Edward and Katherine Rathbun. "Chapter Five – Recognizing Quality Control Problems." Medical Risk Management. Aspen, 1983. Located at Medical and Public Health Law Site. LSU Law Center. Louisiana State University. <http://biotech.law.lsu.edu/Books/aspen/Aspen-INCIDENT.html>.

16 MENTAL RETARDATION BULLETIN COMMONWEALTH OF PENNSYLVANIA * DEPARTMENT OF PUBLIC WELFARE February 18, 2004 6000-04-01.

program, and while residential providers caring for youth before or after the program would have reported incidents as well, any incidents occurring for youth while living with family were not reported. The same discrepancy occurred within schools – incidents were recorded when RESPOND personnel were present, but may not have been recorded in the absence of RESPOND staff. Since these differences existed for many youth, incident counts were artificially low and did not reflect information on these occurrences collected through other means, such as cost data, client records, and anecdotal reports.

*Restraints*

Restraints are mechanisms used when necessary to protect an individual from injuring him/herself or others, or to promote normal body positioning and physical functioning. Restraints come in various forms and can be classified according to the method used to control behavior, such as: mechanical restraints; chemical restraints; seclusion; exclusion and psychological restraints. Restraints will only be applied when less intrusive techniques and imminent danger are present[17]. Individual program plans, developed for residents in accordance with applicable statutes and regulations, have goals and methods aimed at treating and eliminating behavior necessitating the use of restraints. Efforts to reduce the need for restraints are informed by functional behavior analyses. Interventions are developed based on these analyses, and staff members utilize therapeutic approaches such as goal planning aimed at redirecting and releasing aggression through healthy channels, counseling, and withdrawing an individual from an over-stimulating environment[18].

The use of restraints is an indicator of the severity and dangerous nature of an individual's behavior, and an indicator of the success the RESPOND team has in analyzing, preventing and managing such behaviors. Restraints are used as a last resort safety measure, so if the RESPOND team is able to devise effective therapeutic approaches and interventions for managing potentially dangerous behaviors, the number of restraints used per child should be minimal by program discharge.

The use of restraints is one of the pieces of information reported through HCSIS that is included in the incident reports. Therefore, the restraint data faces the same limitations as discussed above for all incident data. Namely, that the use of restraints is not comprehensively recorded outside of the RESPOND program, so usage cannot be analyzed for trends outside of the program window. The discus-

17 "Use of Restraints in Treating Patients/Residents." PA Code. Title 55, Chapter 13. Available at http://www.pacode.com/secure/data/055/chapter13/chap13toc.html.

18 "Use of Restraints in Treating Patients/Residents." PA Code. Title 55, Chapter 13. Available at http://www.pacode.com/secure/data/055/chapter13/chap13toc.html.

sion below touches on the use of restraints outside of RESPOND, but primarily focuses on the trends of restraint usage when residential staff were with and supporting a youth in the program.

Many youth in RESPOND do not require the use of restraints at all during their time in the program. About half of the youth are restrained at least one time, with eight youth experiencing more than ten restraints. Table F lists the number of youth experiencing the corresponding number of restraints.

| Number of Restraints during RESPOND | Number of Youth (n=27) |
|---|---|
| No restraints | 13 |
| 1-6 | 6 |
| 11-19 | 4 |
| 35+ | 4 |

*Table F: Total Restraints per Individual during RESPOND*

The patterns of restraint usage for youth who occasionally require such an intervention appear to vary significantly on an individual basis. Figure 4 displays the restraint patterns for the ten youth who experience the highest number of restraints prior to program entry through one year after discharge. As discussed above, incomplete data pre- and post-RESPOND results in restraint counts for only two youth prior to RESPOND and five youth following RESPOND. These counts are likely low since, in each period, many youth live in family settings where the use of restraints is not reported.

The two youth who experienced many restraints prior to RESPOND experienced very few, if any, during the transition and after discharge. Some youth who experienced restraints during the program experience even more occurrences while working with only the MTT during the transition to a post-discharge residential provider; others have few or no restraints following the program. Other youth experienced few restraints during the program, but experienced more in the year after discharge. It is difficult to determine how much these variances are real or the result of data limitations.

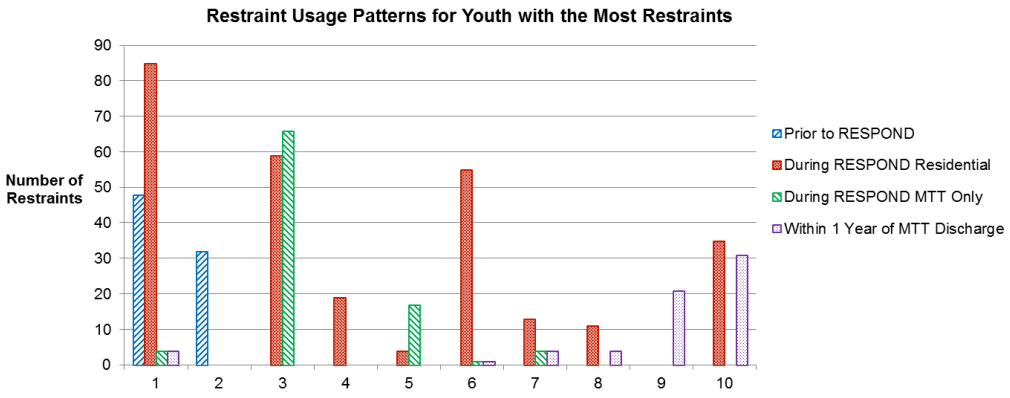



*Figure 4: Restraint Usage Patterns for Youth with the Most Restraints*

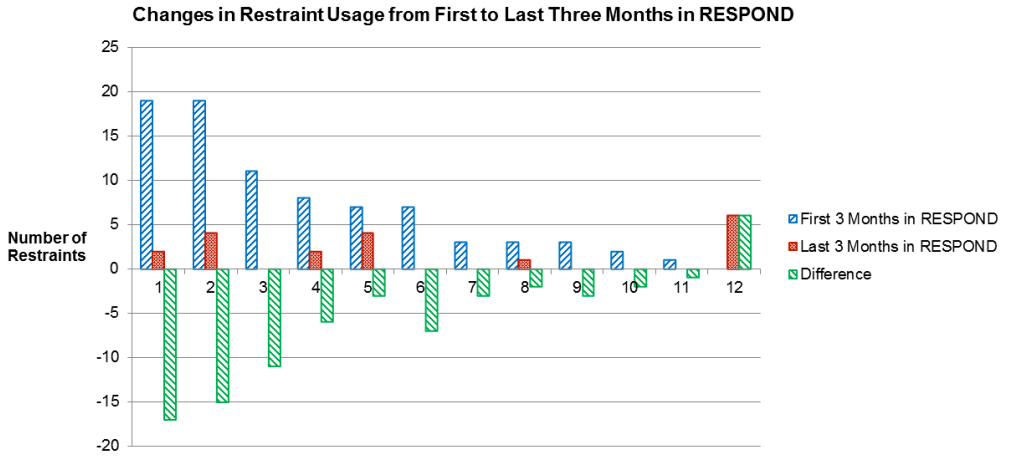



*Figure 5: Changes in Restraint Usage from First to Last Three Months in RESPOND*

As of July 2010, 14 youth were restrained during their stay in the RESPOND residential program. While Figure 4 indicates that most of the recorded restraints for these youth occur while they are in the program, Figure 5 demonstrates that as program staff have time to work with these youth, the usage of restraints consistently decreases from the time of program entry to discharge. Figure 5 charts the number of restraints twelve of these individuals experienced during both their first three months and last three months in the RESPOND program (the other two youth have zero restraints during these time periods). Three youth experienced more than ten restraints in their first three months, and the usage of restraints dropped significantly for all but one youth.

The total number of restraints used in each period dropped from 83 in the first three months to 19 in the last three months. The number of youth requiring the use of restraints also dropped from 11 to six. Since the decrease in the frequency of restraints is substantial and consistent across the RESPOND popula-

tion, this indicates that the RESPOND team has been able to effectively manage the behavior of youth in the program to a degree that minimizes the need to use restraints in order to protect the safety of the youth and others around them.

*Hospitalizations*

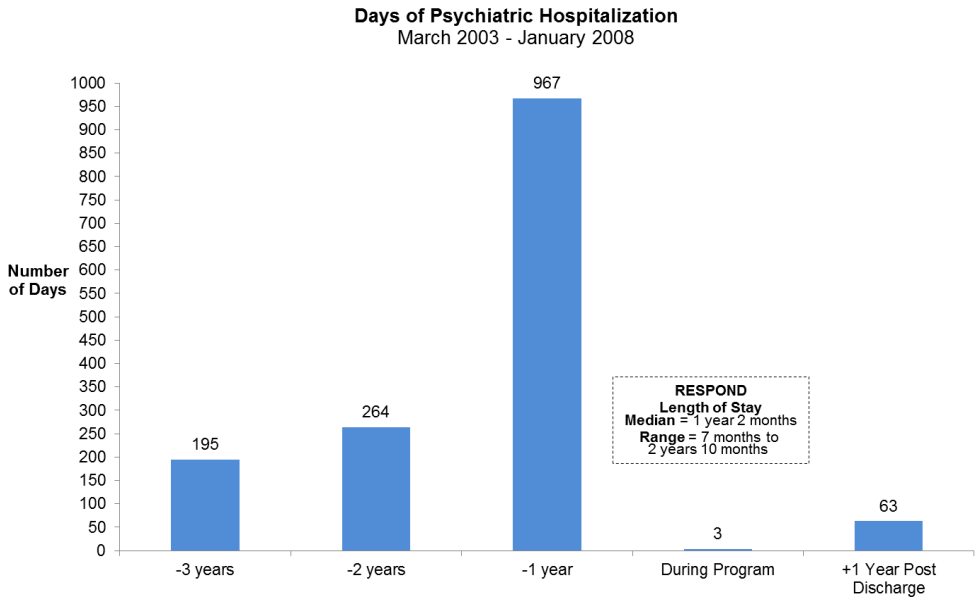
Youth entering the RESPOND program frequently enter inpatient psychiatric hospitalizations prior to program entry. The hospitalization data may not be complete for all youth, but the records that exist show how common it is for these youth to require this emergency intervention. There are four youth for whom we have no data indicating inpatient hospitalizations prior to program entry, but it is unclear if there is a gap in the data or if these individuals never experienced inpatient psychiatric care. As displayed in Table G, at least nine youth experienced six or more psychiatric hospitalizations prior to entering RESPOND, and another seven experienced at least four or five.

| Hospitalizations | Number of Youth |
|---|---|
| 2-3 | 10 |
| 4-5 | 7 |
| 6 or more | 9 |

*Table G: Frequency of Psychiatric Hospitalizations Prior to RESPOND Entry*

Figure 6 displays the total number of days RESPOND participants spent in inpatient hospitalizations relative to their participation in the program. This chart only displays data from March 2003 through January 2008. As the RESPOND population grew, tracking of this information across all potential hospital systems could not be maintained, so complete data are not available through 2011, but there is enough data to confirm that the trend has remained constant. Medical records from hospitals in Allegheny County and cost data from 2008 through 2010 both support the pattern that hospitalizations are frequent prior to program entry and rare following discharge from RESPOND. (Trends in cost data are discussed more thoroughly in the Cost section.) Since the start of the program, only one hospitalization has occurred during RESPOND, as is reflected in Figure 6.

This decline in hospitalizations is noteworthy because hospitalization is an indicator of individuals being in crisis. The challenges they are experiencing cannot be managed or overcome through services administered in the community. The fact that the total days of inpatient care following discharge from RESPOND were low in 2008, and have remained low with time, is a significant indicator of success in that RESPOND participants and their caregivers are not facing the same magnitude of crisis situations they were facing even two or three years prior to program entry.




*Source: Fabry, Bernie. "RESPOND Client Prior Hospitalization Chart." RESPOND program files.*

*Figure 6: Days of Psychiatric Hospitalization*

## Medication Management

Youth entering RESPOND frequently take numerous medications that were prescribed by multiple doctors. In many cases, the medications were not prescribed in a coordinated manner. Once in RESPOND, the MTT conducts a medication analysis in order to find the combination of medications that works most effectively for each individual. The team will modify the dosage or class of medication, one medication at a time, and closely monitor and chart the individual's behavior and sleeping habits in order to determine the impact of the medication change. This process also takes into consideration potential side effects and interactions between medications.

In some cases, medications are based on outdated or inaccurate diagnoses. Not only do medication modifications occur to update and coordinate medications better, but the MTT is also able to work together to ensure that each individual is diagnosed based on current presenting symptoms, and that the medications are appropriate.

Decreases in the number of medications prescribed are often cited as a mark of success for this and similar programs. However, this measure is an output rather than an outcome. Decreasing the number of medications is less important than finding the most appropriate and effective medications for each individual. For this reason, the number of medications is determined not to be an appropriate outcome measure and is not examined in this report.

**Outcome & Process Measures**

## Program Survey (administered by UPMC)

Two WPIC surveys were distributed to the caregivers of youth participating in RESPOND every six months throughout the life of the program. The surveys are part of the WPIC Quality Improvement process and are titled the "Family Empowerment Scale" and "Perceptions of Care." They are voluntary, and at the time of this evaluation, 39 of each had been returned from 17 different respondents. The findings of the "Perceptions of Care" survey are discussed here, as the questions are particularly relevant to the purpose of this report.

Caregivers were asked a number of questions about their views of the services their child was receiving from the RESPOND program. The responses to several of these core questions are displayed below in Figure 7. Overall, responses were very positive. The indicators which scored mostly highly were those relating to how the staff members worked with the children.

There is room for improvement on communication between the staff and the family members. The two indicators with the poorest scores were those asking if staff explained things in a way they could understand, and if the staff listened carefully to the family.

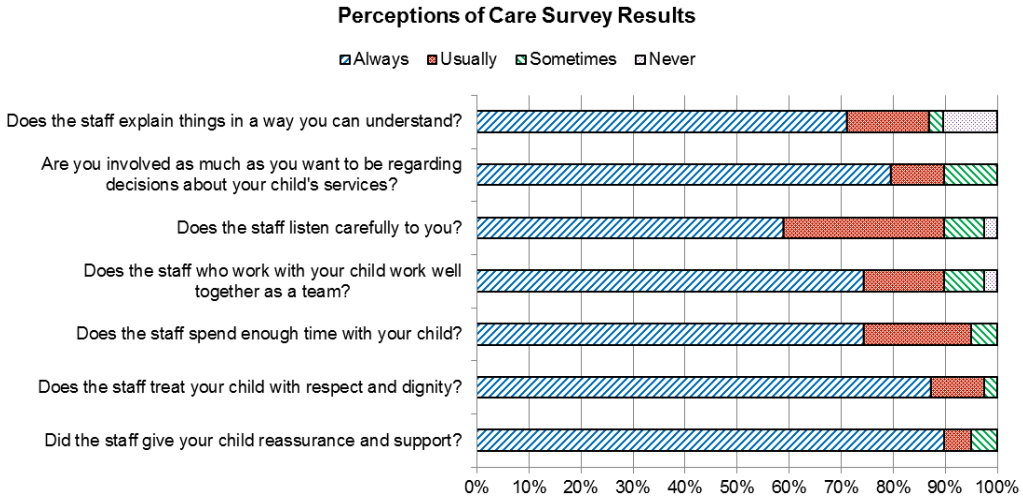



*Figure 7: Perception of Care Survey Results*

## Outcome & Process Measures

In addition to questions with responses on the Always to Never scale, family members were asked to provide feedback on the overall program. One question they were asked that is also discussed during the Interview section of this report is:

*Q. How much is your child being helped by the RESPOND services?*

Half of the respondents reported that their child was helped a great deal. However, about 35 percent responded that their child was not helped at all. Eight unique individuals made this indication at some point, yet three of these had reported a very positive impact in another survey period. This indicates that some families hold varying opinions on the impact of RESPOND at different points in their child's progress through the program. Other families consistently perceive the RESPOND program to have a minimal or a significant impact.

Despite these mixed reviews, all respondents indicated that they would recommend RESPOND to other families facing similar challenges with a Yes response to the following question:

*Q. Would you recommend this facility to someone else whose child needs similar services?*

Additionally, responses to the following question were very positive:

*Q. What is your overall rating of the services your child is receiving through RESPOND?*

On a scale from 1-10, with 10 equaling "best possible care" and 1 equaling "worst possible care," 85 percent of respondents listed a 9 or 10. The lowest score was a 6, with four respondents listing a 6 or 7.

### Discharge Destinations and Length of Stay

Twenty-six youth completed the RESPOND residential program as of the summer of 2010. Of those 26, eighteen were discharged to a residential facility setting, seven returned to their families, and one exited to a juvenile detention center.

Most RESPOND participants were in the program for one to two years (69 percent). Figure 8 illustrates the distribution of lengths of stay for program participants. The amount of time spent in the residential component is supplemented by the time spent working with the MTT and residential staff post-discharge from the residential component of the program. Many youth formally received this ongoing support as part of the transition process. Unless otherwise specified, program involvement throughout the report is discussed in terms of the total length of time youth were receiving services from RESPOND, whether they were in the resi-

dential component or not. This chart shows that this period of time is very similar to the residential program, if not the same, for all program participants.

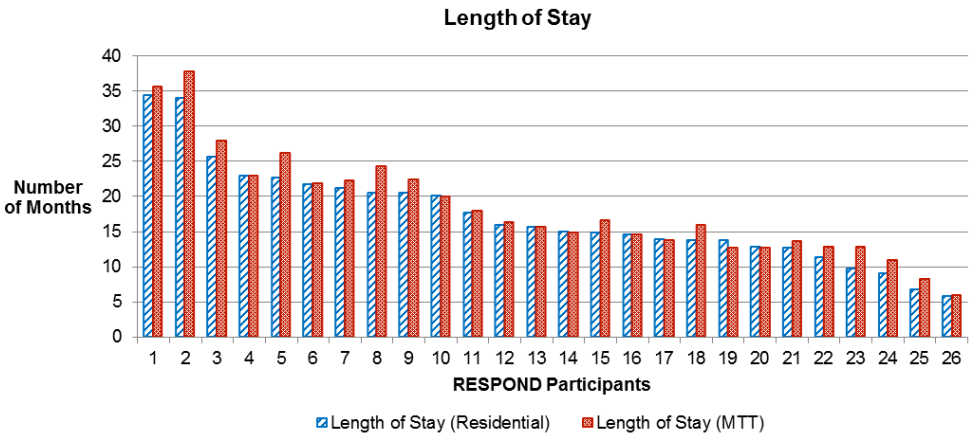



*Figure 8: Length of Stay in RESPOND Program, Both Residential and MTT Components*

Figure 9 displays not only the length of stay in the RESPOND residential program, but also the duration of time in the residential program following the participants' designation as "discharge-ready." The length of stay following designation as discharge-ready was greater than 50 percent of the total time spent in the residential portion of the program for 12 of the 26 youth who completed RESPOND. The youth with few to no months spent in RESPOND after becoming ready for discharge were usually those who exited to their family or remained in care with the same residential provider after exiting RESPOND.

Even though the discharge process planning starts at admission, the process is lengthy because the same agencies that struggled to successfully serve the children prior to entry into RESPOND are hesitant to accept them back. The youth still exhibit challenging behaviors, and while they may have made significant progress during RESPOND, their histories follow them. In addition, other system challenges are present, such as finding or equipping a residence to meet state requirements, hiring and training new staff, or securing the funding necessary for continued care.

Since RESPOND is a service- and cost-intensive program, time lags in discharge and transition after the youth are ready to step down to less intensive residential settings may have significant implications for program cost and sustainability. On average, RESPOND participants spent 7.9 months in the program after designation as discharge-ready. Identifying whether there are strategies available

to transition youth out of RESPOND and into those facilities in a timelier manner may be a systems issue worth further exploration.

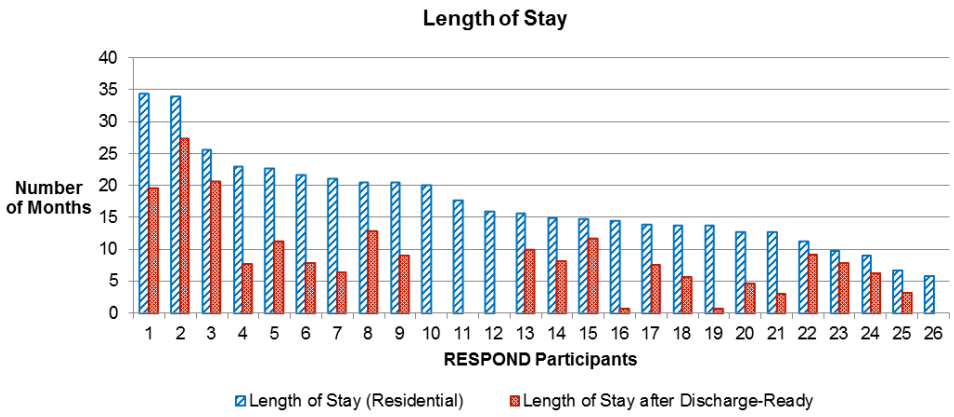



*Figure 9: Length of Stay in RESPOND Residential from Date of Entry and from Date Discharge-Ready*

## Discussion

The analytical power of most of the data is limited since there are not data available on these measures prior to program entry from which to establish benchmarks. In some instances, data collection was limited or inconsistent (see Limitations Section for more information). While this prohibits the data from being used to establish causal links between program participation and outcomes, observations could still be made based on the data.

The outcomes for which there were marked improvement were the number and frequency of hospitalizations program participants experienced, the staffing support youth needed over time, and the number of restraints used during the residential portion of RESPOND. Inpatient hospitalizations were a common occurrence for youth leading up to entry into RESPOND; the number of hospitalizations dropped significantly and remained low during the two years following discharge from the program. This improvement is supported by medical records, cost data, and anecdotal accounts. This represents not only a decrease in an expensive and highly intensive service, but also a significant decrease in the amount of crises these youth experience.

The decrease in staffing needs throughout the RESPOND program was to be expected and reflects the progress youth should make as they enter the program during a time of crisis and are discharged after treatment and behavioral

## Outcome & Process Measures

interventions have improved the participants' behaviors, coping skills, and mental health so that they are able to function and thrive in a less restrictive environment. The fact that the utilization of inpatient services remains low after discharge supports that this is, in fact, occurring.

The restraint data indicated that about half of the youth in RESPOND experienced a restraint at some point during the program. For youth experiencing multiple restraints, most occurred in the beginning of their stay, and the need for restraints declined significantly by the last three months in the program. This is an indication that treatments and behavioral and therapeutic techniques were effective in limiting dangerous behaviors.

The data reflects more moderate gains relative to functioning (CAFAS, Vineland), mental health (Devereux), and acts of aggression. Progress in these areas varies more by individual, with some youth making great gains and others remaining about the same. Very rarely did youth experience more aggression toward the end of the program or score in a more severe range on a functional scale. In nearly all cases, progress ranged from no change to significant improvement.

One measure indicating room for improvement at the systems level is the length of stay following youths' designation as discharge-ready. This length of stay averaged 7.9 months for all youth, and was greater than 50 percent of the total time spent in the residential portion of the program for 12 of the 26 youth who completed RESPOND. Since these time lags have significant implications for program cost and sustainability, any improvements in this area could lead to significant cost savings.

Two indicators that interest many people, but for which no reliable quantitative measures were available, are incidents and medication changes. Incidents and medications may considerably impact an individual's treatment and quality of life, and they cannot be sufficiently evaluated based on output or outcome measures alone. Future evaluation of these indicators should include the establishment of process measures to reveal more details on how incidents and medication changes are handled.

## Interview Results

Interviews with family members were conducted by DHS DARE staff to complement the data recorded by RESPOND staff. The interviews were designed to better understand the perspectives of family members regarding how well the program is addressing the needs of the youth. Interviews of professional staff (not members of the RESPOND staff) who knew the youth well were also conducted since the sample size for family members was very small. A more detailed discussion of the methodology for conducting the interviews is explained in the Methodology section of this report, and the interview instrument is available in Appendix B: Interview Instrument.

The results of the interviews are categorized and discussed below. It is important to remember that the items discussed here are common themes – ideas and experiences that were shared by multiple people. As such, they may not represent every person's individual experience.

### Family Priorities

In order to provide context for the interview results below, this section briefly lists some of the main goals and objectives families said they had for their children when they entered the RESPOND program. These responses identify the challenges these youth and their families were facing on a daily basis, and the items for which they sought help from the RESPOND team.

- Decrease child's violence and aggression towards self
- Decrease child's violence and aggression towards others, including family members
- Acquire daily living skills (e.g. taking dishes to the sink, using the bathroom)
- Increase child's ability to communicate (some children were nonverbal)
- Teach child to respect personal boundaries
- Decrease medications or find the best combination of medications
- Develop a better understanding of their child's behavior
- Decrease disturbing behaviors
- Decrease inappropriate behavior in public
- Increase success/progress made at home
- Plan for the child's future

## Process

At the beginning of the interview, respondents were asked to briefly describe their interactions with the RESPOND team, and a few questions throughout the interview asked about the process of the program. These questions were designed to better understand the family's experience working with the RESPOND program rather than the effectiveness of the program itself, which is discussed in the next two sections.

*Strengths*

- Both families and professionals reported strong communication with the RESPOND team. Multiple parents commented that they were surprised by the level of communication they shared with the MTT. Both families and professionals spoke positively of the monthly meetings, stating that the RESPOND team was willing to share any information in which they were interested. The families were involved in the decision-making process and discussions of goals for the youth. Families felt that the RESPOND team both understood and embraced their goals and priorities for their children.
- Family members were asked to identify the most important things they wanted to see change or improve for their child or grandchild. All families were able to do so, and after identifying these goals, respondents were asked whether they thought the RESPOND team understood these priorities, and if they held the same priorities. The responses to such questions were resoundingly positive, with respondents citing excellent communication and collaboration with the team around goal-setting and decision-making.
- When asked what made RESPOND different from other service offerings, both families and professionals cited the coordinated and comprehensive nature of the program. Other common responses included the expertise of the staff and the broad focus of the program. Families expressed that RESPOND goes beyond other programs and concentrates its focus on daily living skills and how to live safely in society.

*Areas for Improvement*

Areas for improvement relative to process issues were limited and specific to individual families. Overall, families and professionals who interacted with the team were very happy with how the program operated and the level of communication they had with the team.

## Program Effectiveness

Individuals were asked to identify the significant challenges that their child faced and to discuss the progress made on primary goals during the RESPOND program. Some of the main areas in which progress was discussed include daily living skills, aggression, ability to follow directions, behavior in public and diet and nutrition. In addition to progress made by the individual, many family members and professionals discussed the factors in the program to which they attributed the success or lack of success that they reported for their child.

*Strengths*

- Overall, families and professionals were very happy with the MTT. Respondents spoke of the team as very reliable and always available, even after the child was discharged from RESPOND. The whole team worked well together and communicated well with the families and other supports. Most respondents trusted the MTT as experts, and had only good things to report.

  There were a couple of exceptions to this expression of praise. These caregivers seemed to have experienced a communication breakdown with the MTT, or had a strong disagreement with a portion of the prescribed treatment plan, such as the use of medication.

- Respondents consistently reported that the level of aggression each youth exhibited decreased from program entry to discharge. Even family members or professionals who thought the program was inappropriate for the child or had significant shortcomings still cited a decrease in the level of aggression the child exhibited.

- Families and professionals perceived that a set of skills that many youth seemed to both acquire and retain beyond the duration of the program was coping skills. Coping skills are learned skills that help someone bounce-back from being angry, upset, or stressed[19]. These skills have the potential to make a profound impact on RESPOND participants' lives, as these skills will decrease anxiety levels and improve quality of life while impacting their behavior – easing the challenges faced by caregivers as well.

19 "Definitions." Coping Skills for Kids: Brain Works Project. Brain Works and Coping Skills Classroom Project. 2011. http://www.copingskills4kids.net/Definitions.html

- Several people identified that RESPOND staff were very effective at monitoring a child's behavior and redirecting as necessary. This comment was often in reference to children with obsessive tendencies or children who had difficulty transitioning between activities.

*Areas for Improvement*

- Comments regarding the staff at the residential homes were very mixed. Some families expressed great gratitude and love for the staff that cared for their children while in RESPOND, referring to them as part of the family. At the same time, about as many families expressed concerns about some staff members' level of training and some alleged specific instances of inappropriate treatment of their child. While family members commented on the quality of the residential staff more frequently than the professionals who were interviewed, some of the same concerns about adequate training and appropriate behavior were expressed by the professionals.

- Respondents provided mixed reviews regarding the RESPOND team's success in improving or maintaining participants' daily living skills. Some respondents provided very positive feedback, stating that the team was able to teach their child skills that the families never believed the child would be able to learn. At the same time, some respondents felt that some daily living skills deteriorated slightly while in the program.

  The factor that seemed to most influence these responses was the level of daily living skills the youth possessed upon admission into the program. Families that had dedicated a significant amount of time to teaching their children these skills, and had achieved some level of success, were more likely to cite little improvement or a slight decline in skills. Families that had not focused heavily on daily living skills, or who had tried but achieved little success, were much more likely to cite significant improvements.

- A few respondents reported that the RESPOND program was inappropriate for the child concerned. Reasons varied by child, but ranged from a mismatch between child needs and program design to an inappropriate residential environment. While this issue was raised for only a few youth, this is concerning given the small number of total program participants and the expense of the program per child.

## Transition

The transition out of RESPOND is a critical component of the program. The success of the transition has potential implications for how well progress made during the program will be maintained and how well the participant will do in the future. Families and professionals reported very different experiences with their child's transition from the program, so overarching trends are more difficult to identify here than with other aspects of the program. However, overall, the transition was cited as the program's most significant area of weakness. Or, for families reporting only positive experiences, the transition was sometimes the one area in which they thought any improvements could have been made.

*Strengths*

- Families cited that RESPOND team members work well with the new staff that will care for their children following discharge from the program. This collaboration is progressive, beginning prior to discharge from the residential portion of the program, and extending beyond discharge, in order to facilitate a smooth transition. Families appreciated this process and identified it as one of the main reasons for their children doing well in their new settings.

- Some families expressed concern over the anticipation of the transition. RESPOND was the first program that worked for their child, and they did not know how well their child would do leaving the program. Their feedback and stories frequently suggested that their children did better than expected because they handled transitions and were able to cope with change much better after RESPOND than they had been able to before entering the program.

- Most families felt that the transition out of RESPOND and into a new residential setting, or back into the home, was a very supportive process. If the child entered a new residential setting, families discussed how the team helped them to identify appropriate placement options and supported the transition to these settings by working with the new staff as their child adjusted to the new environment. For families with children returning home, some parents said they received training from the RESPOND team, and many commented on the availability of the team if they had any questions or concerns, even after their child left the program.

*Areas for Improvement*

- Both parents and professionals whose children were adolescents voiced concerns that the RESPOND program was not age-appropriate and did not prepare youth to transition into the adult system after discharge. As one individual said, "He would've been fine if he was younger and transitioning into an adolescent home, but he needed to be taught different things [self-regulation skills] going into the adult system… In the adult system, his diet would not be monitored for him, and there is not oversight to intervene in his obsessions and compulsions."

  One of the main concerns related to the difference between the two systems is the degree of self-determination. Youth were monitored well in the RESPOND program and had high staffing ratios. As one professional stated, "If you have three adults watching you as a teenager, it doesn't teach you to do things for yourself. That's why he did better with [services provided one-on-one]."

- The transition into new residential settings was challenging for a couple of the youth because the staff assigned to work with them were not appropriate for their needs. For example, some youth with aggressive tendencies do not respond well to weaker personalities and will take advantage of these individuals. In these circumstances, staffing adjustments were made, and situations improved. If these mismatches had been anticipated and addressed in advance, the transition process might have gone more smoothly.

- A couple of the youth experienced difficulty during their transition because of a breakdown in communication, which led to a lack of sufficient planning. The communication deficit caused key events and stakeholders to be left out of the transition process and/or caused concerns related to the transition to go unaddressed. This issue was raised with only a couple of youth, so progress may have been made by the RESPOND team over time. However, the importance of maintaining strong communication among all stakeholders during the transition remains a key finding from the interviews.

## Long-Term Impact

In addition to program effectiveness, respondents were asked to reflect on the long-term impact of the program. These questions were asked to better understand whether specific interventions or improvements that were made during RESPOND continued to be maintained following discharge from the program when service levels decline to less intensive levels. The ability to maintain progress in the long-term is an important indicator of program effectiveness, and has a significant impact on treatment costs in the future.

*Strengths*

- As mentioned above, coping skills were gained or improved upon by many RESPOND participants. When asked if these skills were maintained after transitioning out of RESPOND, responses were very positive. This was the one set of skills that youth consistently retained over time.

- Some parents reported that they learned how to work with their children, and the service system, more effectively. This comment most often came from parents who were engaged throughout the whole process. This knowledge came from working through the process to access RESPOND services, and through working closely with the RESPOND team. Some received resources (e.g. paperwork, books) from the RESPOND team that they found very useful, and others maintained contact with the MTT after their child was discharged from the program, seeking counsel when needed.

*Areas for Improvement*

- As expressed in the Transition section, both parents and professionals expressed concern that the RESPOND program did not adequately prepare youth to enter the adult system after discharge. This match between services provided and youths' needs impacts the likelihood of progress being maintained over time since the youth will need to be more responsible for their own actions and behaviors. Individuals observing these youth as they transitioned into the adult system reported that they needed to have learned more self-regulation skills than if they had entered the adolescent system, because the level of oversight is so different.

- Multiple respondents commented that the staff members of the new residential settings are not as well trained as the staff in the RESPOND program. While this reflects positively on the quality of staff in the RESPOND program, this concern from respondents is important to capture

because the expertise of individuals in the new residential settings will have an impact on RESPOND participants' development and stability in the years following RESPOND. In order to sustain the progress made while in RESPOND, it is important that individuals responsible for the care of participants after program discharge possess the skills necessary to maintain and improve upon the progress already made.

### Discussion

One potential weakness of these interview results is the low representation of youth with limited family involvement during the program. It was very difficult to identify natural supports or professional contacts to speak to about youth with few or no family ties. If the experiences of these youth varied significantly from those with family involvement, they may not be adequately represented in these results.

Aside from this concern, the responses appear to be fairly robust, as feedback from families and professionals who cared for youth in the RESPOND program varied from positive to negative. Individuals who participated in the interviews ranged from parents who felt their "family was saved" by the program and are therefore strong advocates for RESPOND, to parents who were very dissatisfied with the program, to professionals who felt the program "was a Godsend" for the child, to professionals who felt the program was not appropriate for the child. Opinions and emotions about the impact of the program were strong, and could not all be conveyed effectively here in this summary of trends in strengths and areas for improvement.

Overall, perceptions of the RESPOND program and the team of staff working with the youth were very positive. In the end, families felt that their children were better off for having been in the RESPOND program, and many said they did not know what they would have done without RESPOND. Respondents appreciated the great working relationship they had with the RESPOND team and were often surprised by the gains they witnessed in the children as they progressed through the program. Multiple families shared that they considered specific members of the MTT and the residential staff to be part of their family.

## Interview Results

Individuals who expressed concerns related to the program frequently cited a specific incident or individual with whom they had a poor experience. The family members that were interviewed were very protective of and invested in their child's wellbeing, so they were very vocal relative to concerns they had about their child's treatment or environment. These concerns are represented in these findings and should be taken seriously as items on which to improve. However, they should not overshadow the gratitude expressed by families for the impact RESPOND made on their children's lives and on their families' lives. Families with these concerns often saw them as a critical element to improve within a larger program that had the potential to make profound impacts on children's lives.

## Cost Analysis

Since RESPOND is such an intensive program, significant costs are incurred per individual served. The goal for the intensive care is to not only improve the participants' quality of life, but also provide stability and an understanding of appropriate care and treatment for each individual that can be sustained over time, saving treatment costs in the long run. From January 1999 to August 2010, the public cost of serving RESPOND consumers amounted to about $27,000,000. The average cost was $926,000 per individual, and the median was $823,000. The analysis presented in this section is designed to investigate if this goal of future cost savings is being met.

The program costs examined here represent the public cost of providing care for RESPOND participants[20]. Any services received through private or employer-provided insurance are absent from the data. The cohort studied in this section includes the 30 consumers entering RESPOND from the beginning of the program through September 2010. The cost study covers the period extending from two years prior to admission into the RESPOND residential unit until two years following discharge from the MTT. The RESPOND time period includes involvement with the MTT after discharge from the residential unit because services are still administered at a high level by the RESPOND team during the transition period (see Methodology for more information). Sixteen individuals were discharged from RESPOND at least two years prior to the study and have average daily costs recorded for the entire study period.

Several factors impact the cost of service provision both within the community and in residential settings. These factors include the types of services/care required, the level of care provided to each consumer, the intensity of supervision necessary to support each consumer, and the level of support provided by family and other natural supports.

This section analyzes costs by first reviewing cost and service level trends over time, and then testing for statistically significant changes in both cost and unit-hours of service. Costs are then analyzed categorically, by inpatient, prevention, and intervention services. Finally, important costs and benefits that are not quantified but are still important to consider are discussed in the conclusion of the section.

20 Throughout the analysis, the following two assumptions are maintained. First, services billed by different providers under the same service coding are, in fact, the same service. Second, service providers' fees are alike for similar services.

## Cost and Service Trends

Service levels and costs were not constant for each consumer over the study period. Figures 10 through 12 display costs and service levels indexed by time, providing average daily costs and unit-hours of care[21]. Figure 10 charts the average daily cost for each consumer during the specified time periods. For most clients, there is an increase in spending until admission into the RESPOND program. Some clients' data shows a decline just prior to entry, with the point of heaviest usage occurring three months prior to admission to RESPOND. This may occur for some youth because they come to the attention of the MSRRT during the peak of their crisis, and some planning and services are able to be administered effectively prior to their entry, causing costs to decrease slightly in the month prior to admission to the RESPOND residential program.

Some consumers incurred costs much higher than their peers prior to entry into RESPOND. These individuals were among the heaviest users of psychiatric hospitalizations. Three of these four consumers were active in RESPOND during this study, so their average daily costs during RESPOND and after discharge were not available. However, since their pre-RESPOND costs are driven by inpatient services, costs for these consumers are expected to drop into the range experienced by other RESPOND consumers after the intervention, when crisis inpatient care is no longer needed.

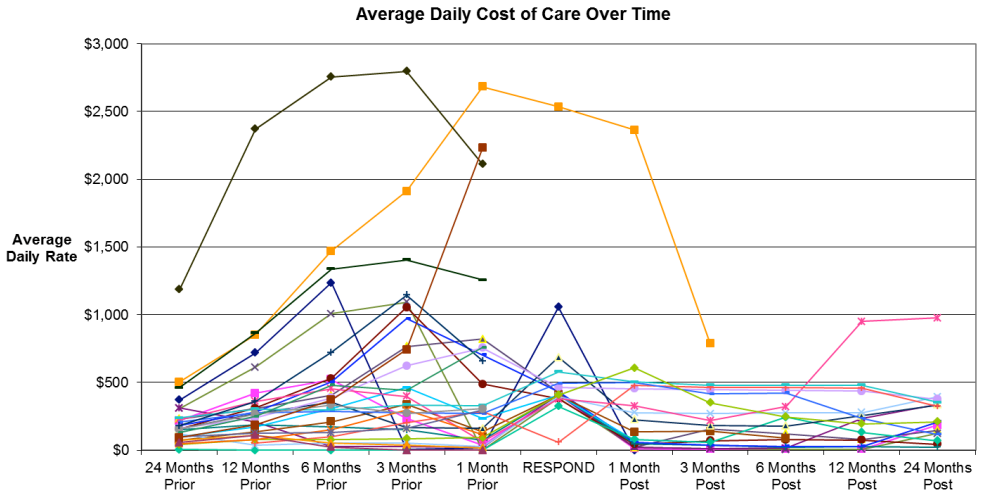



*Figure 10: Average Daily Public Cost of Care for each RESPOND Consumer*

21 Unit-hours of care are increments of time reported for billing purposes.

The average daily cost for all youth is skewed by the costs of the specific services. As indicated above, an example of such a service is psychiatric hospitalization, which is significantly more expensive than outpatient treatment. While it is important to examine the costs of these services, it is also important to consider the level of services provided, absent costs. Figure 11 displays the average daily unit-hours of care used by each youth. These figures represent the level of care each person requires in a different manner by examining the average number of staff hours dedicated to their care in each time period.

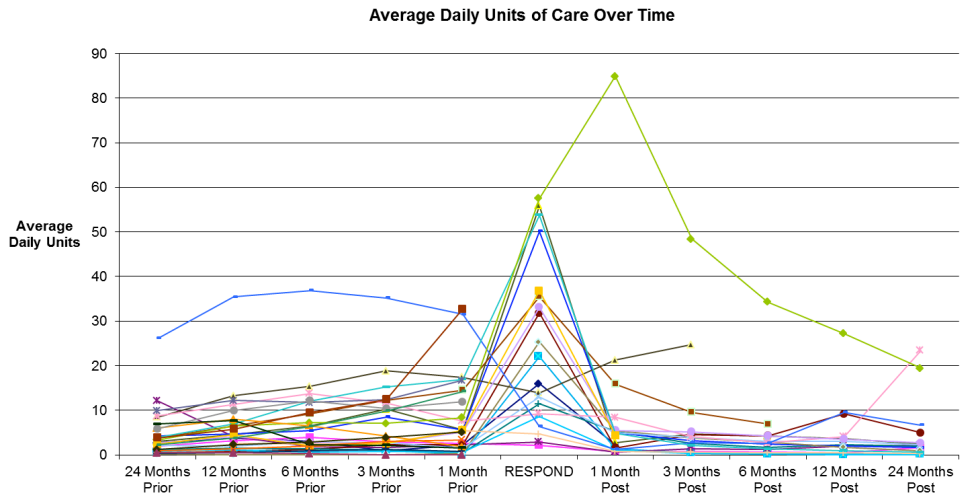



*Figure 11: Average Daily Unit-Hours of Care for each RESPOND Consumer*

Many of the RESPOND consumers have similar patterns of service demand. They experience a slow and steady increase in service demand until entry into RESPOND. Service levels increase sharply and peak while in the RESPOND program. Demand then declines sharply in the month following RESPOND for the majority of youth, and remains stable at that lower level for the following 24 months. The average daily unit-hours post-RESPOND are lower than those pre-RESPOND.

The trends in daily unit-hours displayed in Figure 11 differ from those for costs, as displayed in Figure 10. Figure 12 charts the average daily costs and unit-hours for all consumers on the same chart in order to illustrate these differences more clearly. The average daily units of service increase slowly over time until the youth enters RESPOND. At entry, this intensive program increases the average daily units of service more than threefold. Following RESPOND, the units decrease drastically, remaining slightly higher than pre-RESPOND levels during transition, but then falling below the average daily units in the twelve months prior to RESPOND.

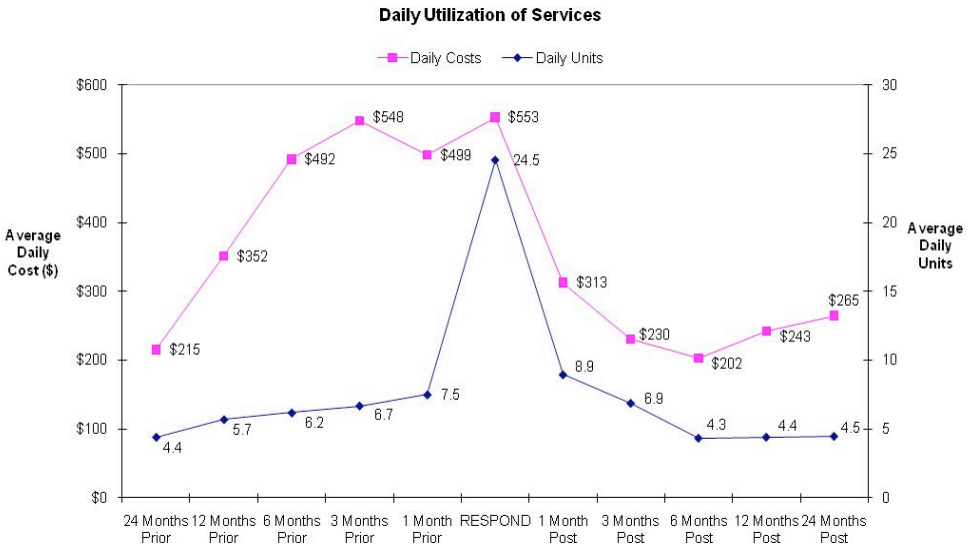



*Figure 12: Daily Utilization of Services: by Cost and Unit-Hours*

The trend for the average daily rate is somewhat different. While the number of service units pre-RESPOND are one-third the number of units during RESPOND, the costs are just as high. The costs are high even though service levels are lower because of the types of services consumers are utilizing at this point. Psychiatric hospitalizations – a very costly service - were frequent for RESPOND participants prior to program entry. These costs drive the average daily rate. (Inpatient costs are explored in more detail below.) Still, the RESPOND daily cost is higher than any other cost, but it helps control future costs. At the peak of the intervention, the average daily rate is $553 per day. The highest average daily cost in the two years following RESPOND falls and remains below the average costs of service within the year leading up to RESPOND.

## Cost Comparison of RESPOND

In order to see if RESPOND has a statistically significant impact on the cost or level of care provided to RESPOND participants, a Wilcoxon Signed Ranks Test was conducted to compare the costs and unit-hours of care before, during and after RESPOND. The Wilcoxon Signed Ranks Test is preferable to the Paired Samples Test because the data is skewed. The Paired Samples test assumes a normal distribution of data, whereas the Signed Ranks Test does not. The average rates two years prior to entry are compared to the average rates during RESPOND, and two years post discharge.

## Cost Analysis

Table H provides the descriptive statistics for these variables. Units of care and cost post-RESPOND have four fewer observations than the other variables because some youth included in the study completed RESPOND less than two years ago. Their costs will be excluded from tests requiring post-RESPOND cost and service data.

*Descriptive Statistics*

| **Variable** | **Description** | **Count** | **Mean** (std. error) |
|---|---|---|---|
| RESPOND Units | Average daily unit-hours of service during participation in RESPOND residential and MTT | 20 | 24.52 (4.18) |
| Units pre-RESPOND | Average daily unit-hours of care in the 24 months prior to entry into RESPOND | 20 | 12.28 (4.63) |
| Units post-RESPOND | Average daily unit-hours of care in the 24 months following discharge from RESPOND | 16 | 4.47 (1.72) |
| RESPOND Cost | Average daily cost of service during participation in RESPOND residential and MTT | 20 | $552.88 ($112.03) |
| Cost pre-RESPOND | Average daily cost of care in the 24 months prior to entry into RESPOND | 20 | $368.00 ($62.63) |
| Cost post-RESPOND | Average daily cost of care in the 24 months following discharge from RESPOND | 16 | $264.58 ($56.60) |

*Table H: Descriptive Statistics for Cost and Service Variables*

The results of the Wilcoxon Signed Ranks Test are presented in Table I and reveal that statistically significant differences at the 95 percent confidence level only existed when comparing costs and services incurred during RESPOND to the pre- and post-RESPOND periods. The differences were significant for each of these comparisons. This is not unexpected given the intense nature of RESPOND. It is notable that there is a significant difference in the average cost per consumer prior to RESPOND and during RESPOND since costs in the six months prior to program entry were nearly as high as during the program.

| | Signed Ranks Test Z value (p-value) |
|---|---|
| Units pre-RESPOND: RESPOND Units | -2.240 (.025)[1] |
| Units post-RESPOND: RESPOND Units | -3.051 (.002)[1] |
| Units post-RESPOND: Units pre-RESPOND | -1.758 (.079)[2] |
| Cost pre-RESPOND: RESPOND Cost | -2.053 (.040)[1] |
| Cost post-RESPOND: RESPOND Cost | -2.172 (.030)[1] |
| Cost post-RESPOND: Cost pre-RESPOND | -1.344 (.179) |

*Null hypothesis: θ = 0*
*1 Significant at the 95% level*
*2 Significant at the 90% level*

*Table I: Signed Ranks Test Results*

The two indicators for which the differences are not statistically significant may arguably be the most interesting. The differences in average costs and unit-hours of service pre- and post-RESPOND are not significant at the 95 percent confidence level, even though the average cost and service level do vary by a wide margin between periods ($103.40 and 7.8 unit-hours).

This test is important since these are the costs and service levels incurred by RESPOND consumers outside of the temporary intervention, and one of the goals of RESPOND is to reduce these pre-RESPOND levels in the long run. While the charts and figures display a decrease in costs and services following discharge from the RESPOND program, the test does not reveal a statistically significant decrease in costs or services. This may be caused by the small sample size and variance in the data. The magnitude of the differences, as demonstrated in the descriptive statistics and the charts, suggests that retesting the data once the sample has grown may reveal statistically significant findings.

## Inpatient Services

The largest factor contributing to high daily costs of care prior to RESPOND for many youth is inpatient psychiatric hospitalizations. In the six months prior to entry into RESPOND, 73 percent of all money spent on RESPOND consumers was spent on inpatient psychiatric services. This compares to only 17 percent of total costs in the six months following discharge from RESPOND. This marked shift indicates a significant positive change in the stability of RESPOND participants' behavior and mental health.

Figure 13 charts the average daily public cost of psychiatric hospitalizations in each of the specified time periods. Some inpatient stays occuring outside of Allegheny County or through private funding streams are not recorded here, but these estimates do fully reflect the costs to DHS, and are an accurate representation of the trend in inpatient care.

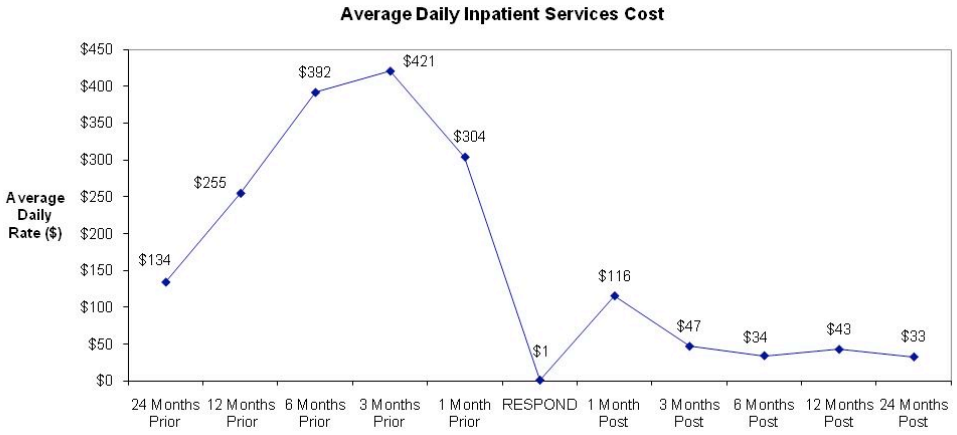



*Figure 13: Average Daily Inpatient Services Cost*

Psychiatric hospitalizations were rare during RESPOND since most of the services provided in that setting could be provided by the RESPOND team. Among all 30 participants, only one hospitalization has occurred to date. Following RESPOND, the number of inpatient stays remained very low; the average public costs of psychiatric hospitalizations in the post-RESPOND period never reach the lowest average cost in the pre-RESPOND period.

## Prevention versus Intervention Services

Services provided to consumers can be divided into prevention and intervention services[22]. The difference between prevention and intervention services is that prevention services are designed to avert the development of a problem or address an issue in a way that removes the need for unnecessary system involvement. Intervention services address an existing condition or need and are designed to decrease or cease the duration and reduce the severity of the condition. A few of the major prevention services include: home and community habilitation, children's psychosocial rehabilitation, and respite services. Intervention services include services such as: case management, behavioral health rehabilitation services (BHRS), psychiatric inpatient hospitalization, community residential services, and community treatment teams.

22 Categorizations used in this report are based on the guidelines established by the DHS Office of Administration and Information Management Services in conjunction with other DHS offices.

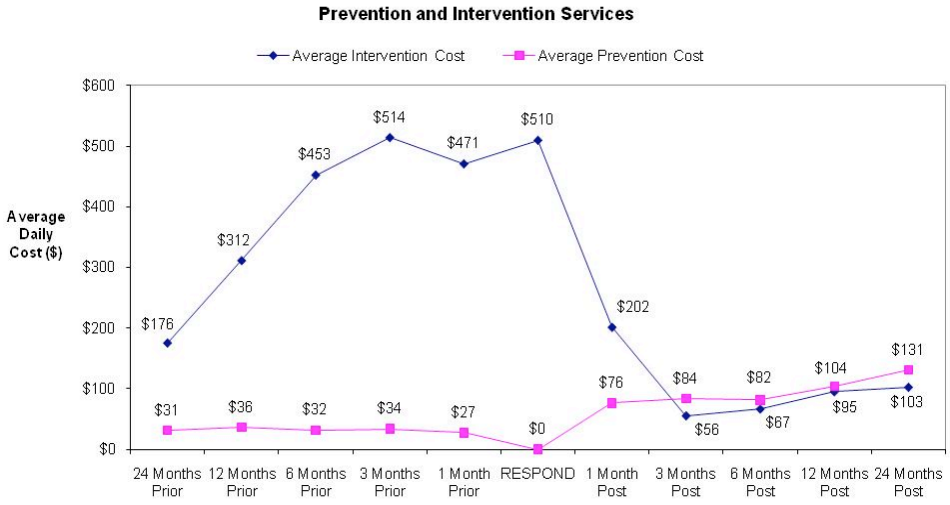



*Figure 14: Average Daily Cost of Prevention and Intervention Services*

Figure 14 charts the average daily expenditures for each category of service across time. The data show that:

- The average daily cost of intervention services decreases significantly following RESPOND. Even though costs increase slightly the longer someone is out of RESPOND, these costs still do not reach the level they were at two years prior to RESPOND.
- The main drivers of the decrease in the cost of intervention services are the decreases in case management, inpatient hospitalizations, and mental health crisis intervention.
- Prevention services were steady prior to admission into RESPOND and then virtually disappear during RESPOND. Following discharge from the program, prevention costs increase with time, more than doubling their previous level within one year. The utilization of prevention services is strengthened during the transition out of RESPOND, when a service plan is put in place for the consumer.
- Although prevention costs are greater following RESPOND, the intervention costs remain so low that the total costs of care for RESPOND consumers remain lower following RESPOND than they were prior to entry into the program. The reliance on more prevention services versus intervention also suggests that the experience in RESPOND helped individuals transition from crisis response to following a more deliberate service plan.

## Discussion

The average daily costs and service units displayed over time in Figures 10-12 imply that costs are substantially lower following discharge from RESPOND than they were prior to entry. The difference in the average cost of care from the two years prior to RESPOND and the two years following RESPOND was $103.40 per day. However, statistical analyses show that the difference is not statistically significant. This does not mean that the difference is not real and consistent over time; rather, with a sample size of 16, it indicates that not enough data are available to prove statistical significance at this time.

The costs that decreased most dramatically are those for inpatient services. The share of costs dedicated to psychiatric hospitalizations dropped from 73 percent in the six months prior to RESPOND to 17 percent in the six months following discharge. Since hospitalizations were such a large share of total costs prior to RESPOND, decreasing the need for inpatient services significantly impacted total costs of care for RESPOND consumers.

In the two years following RESPOND, prevention services are utilized more than during any other period. At the same time, intervention services are kept lower than during any other period, resulting in total costs remaining low. Total costs do begin to rise slowly the longer that participants are out of RESPOND, and it is unknown how much these costs will continue to increase over time. However, the continuing reliance on prevention services over the 24 months following RESPOND suggests that the gains made during the program are maintained, as crisis services are not being utilized and prevention services continue to be tapped.

There are many costs and benefits associated with the services and care provided for RESPOND participants that we were not able to include in this analysis. Some of these costs can be quantified, but are not here because the data are unavailable. Other costs and benefits cannot be quantified, but impact people in meaningful ways that need to be considered in a cost-benefit analysis. While we cannot quantify them, each of the significant factors identified here is discussed briefly. These factors include:

- Private costs of care (including living expenses)
- Opportunity cost
- Family stress/strain
- Safety (personal and safety of others)
- Home stability

*Private Costs of Care*

Families who care for their children at home experience greater private costs than families whose children live in a residential setting, and these private costs of care are absent from the data. These costs are often real expenses that families make for personal care and basic living expenses, but they also include public cost savings since the child is not in a residential setting.

The average daily residential cost (excluding the costs of nursing care) for occupancy in 2- to 4-person Waiver-funded homes in Allegheny County is $390. The median cost is $340. This amounts to an average of about $11,870 per month[23]. These costs reflect living expenses and home maintenance, but also staffing. The equivalent to staffing costs for a family would be their opportunity cost (discussed further below).

Not only are these costs important because they highlight the difference in public costs of care based on where an individual is residing, but there are also implications for these costs relative to the effectiveness of the RESPOND program. If RESPOND enables children to return to their families rather than a residential setting, significant public costs can be avoided. Additionally, the majority of costs incurred prior to RESPOND were for inpatient services, usually when the family was in crisis and could not safely manage their child in the home. If the RESPOND program is effective in impacting long-term functioning, the youth who return to their families' homes will rarely require hospitalizations due to a crisis. The resulting increases in safety and stability will decrease private costs of care and public costs associated with inpatient services.

*Opportunity Cost*

In addition to the physical and material costs of care families realize when caring for a loved one at home, caretakers also experience an opportunity cost. If a family member requires constant supervision, at least one person in the household must dedicate his/her time to supervision throughout the day, preventing engagement in other activities. These activities could include employment, but could also include any other activity that the person would benefit from or find enjoyable. The opportunity cost is the loss (either direct or indirect) experienced by the individual because he/she chooses to spend his/her time one way rather than the next best alternative. If one wished to quantify this cost, it would be equal to the value the individual would place on engaging in that activity, or the amount of money he/she would earn.

23 Costs provided by DHS Office of Intellectual Disability, based on provider cost reports as of January 2011.

*Family Stress/Strain*

The responsibilities and challenges that caregivers experience while caring for a child with challenging behaviors are numerous. These responsibilities are often compounded by other factors, such as caring for other children and family members in the home or holding a job. The combination of these responsibilities and challenges has the potential to put strain on a family and generate a significant amount of stress. This strain can have significant costs, and may be manifested through social, emotional, or physical harm.

In the interviews, multiple parents lamented the fact that they wanted to have their loved one at home, but realized that they were not able to both adequately care for their child and maintain a safe and sustainable living environment for the rest of the family. These parents expressed mixed emotions as they spoke of the relief that accompanied their child's entry into the RESPOND program. They also spoke of RESPOND as a program that "saved their family," as the strain of caring for a child with challenging behaviors consumed their whole life, complicating each family member's ability to foster a relationship with others in the family. As a staffed program, RESPOND was able to provide youth with the structure and level of supervision necessary to maintain a safe environment, adjust treatment, and teach them essential skills that would allow them to return safely to the home or a residential setting. This intervention had a great impact on families' health, regardless of where the child moved to after discharge from the program.

*Safety*

Costs may be associated with some of the consequences that result from a lack of safety, such as hospitalizations or medical care. However, many costs and benefits associated with safety are not quantified. Feeling safe impacts mental health in addition to physical health, and is one of the most basic human needs. The role that safety plays in the lives of RESPOND participants is paramount, as the lack of safety experienced by a child with challenging behaviors or his/her family members is often the impetus that pushes a family to seek the assistance of the RESPOND program.

*Home Stability*

The home instability many youth experienced prior to entering RESPOND, due to their challenging behaviors, was outlined in the beginning of this report. After discharge from the program, children live in much more stable environments, which have had a very positive impact on social and emotional development. In some circumstances, this may impose a greater cost on the public system, and it is important to factor in the benefits experienced by the individuals in addition to these costs.

# Conclusion

The RESPOND program serves youth with challenging behaviors that are associated with very complex needs. Many enter the program as a last resort after other systems and services have failed to make any progress and the youth are no longer safe in their current setting. The findings presented in this report represent three different methods for analysis of programmatic success; these methods are the analysis of outcome and process measures, interviews with natural and professional supports, and trends in public costs.

## Outcome and Process Measures

The analysis of outcomes revealed that there were limited data upon which to evaluate the effectiveness of the RESPOND program. If there is interest in establishing causal links between RESPOND and outcomes for youth, more outcome measures need to be developed and benchmarked, and relevant data would need to be collected in an ongoing and systematic fashion.

The data did reveal that there were marked improvements in psychiatric hospitalizations, staffing ratios, and the use of restraints. After entering RESPOND, the treatment and behavioral interventions administered by the RESPOND team allowed the youth to function in a less intensive environment with less oversight, and this continued after discharge from the program. In these environments, youth were also significantly less likely to encounter crisis situations that would result in psychiatric hospitalizations or require the use of restraints.

Youth also made moderate progress on indicators for aggression, functional behaviors and mental health. Progress in these areas varied by the individual, with some youth experiencing little-to-no change and others experiencing a substantial improvement.

No indicator or measure showed a post-enrollment decline in RESPOND youths' performance or progress. However, one indicator showing room for improvement at the systems-level is the length of stay following youths' designation as discharge-ready. This length of stay was greater than 50 percent of the total time spent in the residential portion of the program for 12 of the 26 youth who completed RESPOND. These time lags have significant implications for program cost and sustainability. On average, RESPOND participants spent 7.9 months in the program after designation as discharge-ready.

## Interviews

Interviews with caregivers and professionals who worked closely with the youth participating in RESPOND helped to clarify program strengths and areas of improvement from the families' and the professional supports' perspectives. The interviews revealed a spectrum of experiences and opinions, ranging from

positive to negative. Regardless of individual perspectives on specific aspects of the programs, all participants felt that the program as a whole made a positive difference in the lives of these youth and helped caregivers to better understand and work with the system of services available to their child.

Families repeatedly identified the following items as strengths of the program: the coordination of services; communication with the RESPOND team; the expertise and impact of the MTT; their child's development and maintenance of coping skills; and the overall impact the program made on their child's and their family's life.

Two primary areas for improvement were identified by multiple respondents. The first was to better prepare adolescent youth for their transition into the adult system of care where they need to be more independent and possess more self-regulation skills. The other identified concern was the competency and appropriateness of some of the residential staff caring for the youth, both during RESPOND and following discharge.

The transition out of RESPOND was identified by many as a challenging and critical point in the process. Some youth had great experiences (exceeding the expectations of their families), while others did not, struggling through the transition a good bit. The interviews indicated that the potential cause for these differences was communication: families experiencing a great transition commented on how well everyone communicated and collaborated throughout the process, and difficulty during transition often seemed to be tied to some form of communication breakdown.

## Cost Analysis

The intensive care provided during RESPOND is designed to not only improve the participants' quality of life, but also provide stability and an understanding of appropriate care and treatment for each individual that can be sustained over time, saving treatment costs in the long run. The average public cost of care per individual from January 1999 to August 2010 was $926,000, and the median was $823,000. Costs for each individual vary over time – climbing just prior to entry into RESPOND as youth were in crisis and heavy users of inpatient psychiatric hospitalizations. Costs peaked during RESPOND and then fell sharply after discharge. The average difference amounted to $103.40 per day.

## Conclusion

Trending of categorical spending revealed that the composition of services generating costs changes markedly between the two periods of time. Prior to RESPOND, nearly all expenses are for intervention services – in fact, 73 percent of all spending is for psychiatric hospitalizations. Following RESPOND, costs for prevention services surpass intervention services, and inpatient hospitalizations are responsible for only 17 percent of costs.

In the two years following RESPOND, intervention services are kept lower than during any other period, resulting in total costs remaining low. The continuing reliance on prevention services over the 24 months following RESPOND suggests that the gains made during the program are maintained, as crisis services are not being utilized and prevention services continue to be tapped.

### Summary

Overall, the combination of outcome data, interviews, and cost data illustrate a coordinated team of experts who communicate well with the family and other stakeholders to tackle the challenges youth with complex needs experience on a daily basis. This collaborative effort results in treatment that is more effective than any received by these youth in the past, and the impact is sustained beyond program discharge. The youth enter more stable living environments, require fewer and less costly services, and experience fewer crises. Service utilization is concentrated in preventive services. Caregivers and treatment providers better understand how to work with the youth, improving the youths' quality of life, increasing safety, and decreasing caregiver stress.

Appendix A

## Individual CAFAS Scores by Domain

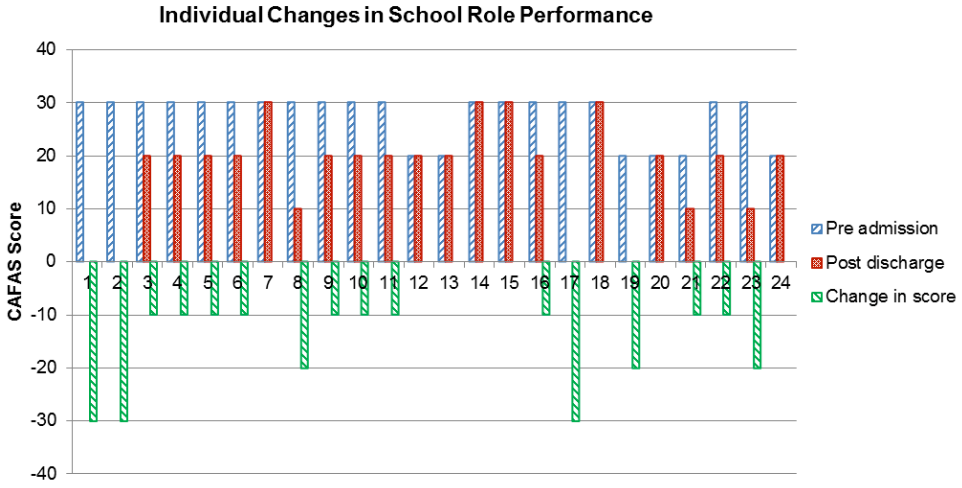



Figure 15: Individual Changes in CAFAS Domain: School Role Performance

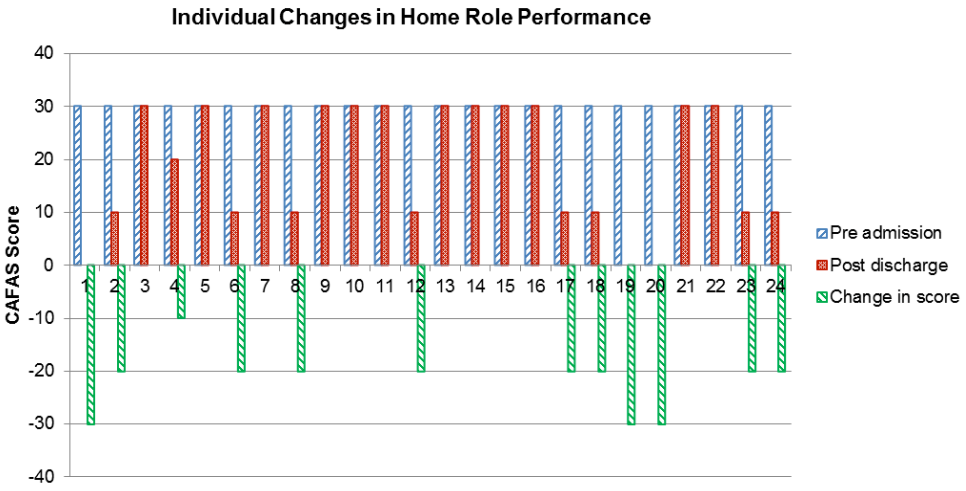



Figure 16: Individual Changes in CAFAS Domain: Home Role Performance

## Appendix A

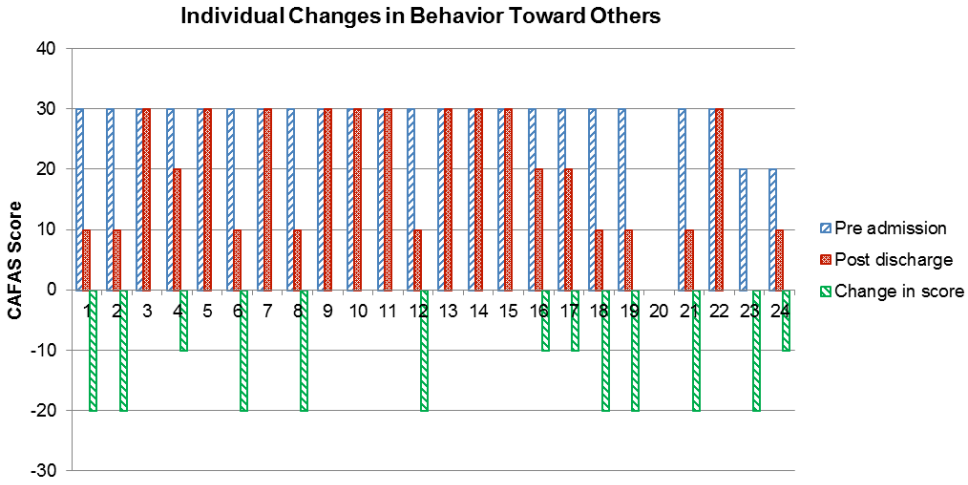



Figure 17: Individual Changes in CAFAS Domain: Behavior toward Others

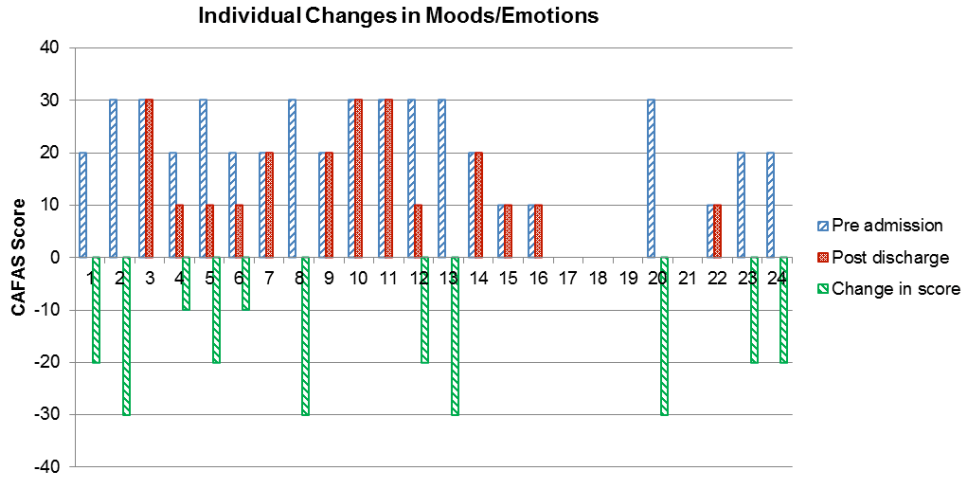



Figure 18: Individual Changes in CAFAS Domain: Moods/Emotions

## Appendix A

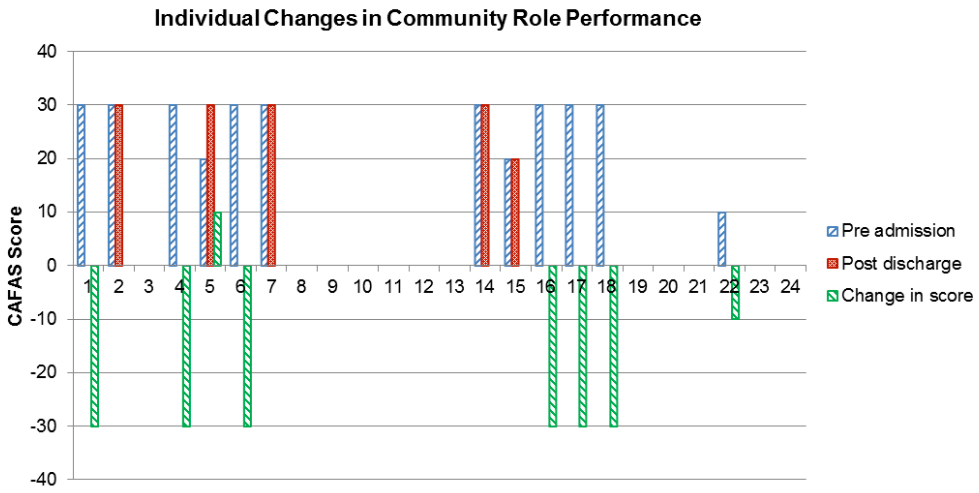



Figure 19: Individual Changes in CAFAS Domain: Community Role Performance


Figure 20: Individual Changes in CAFAS Domain: Self-Harmful Behavior

## Appendix A

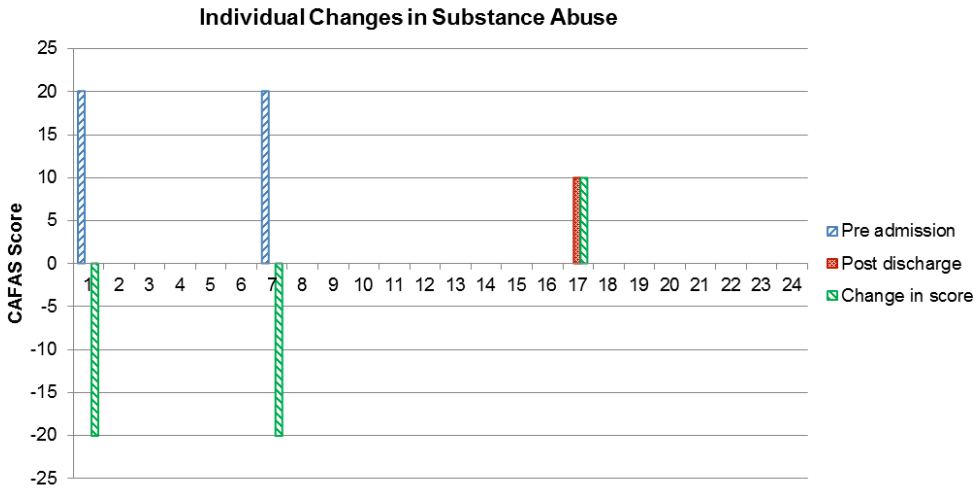



Figure 21: Individual Changes in CAFAS Domain: Substance Abuse

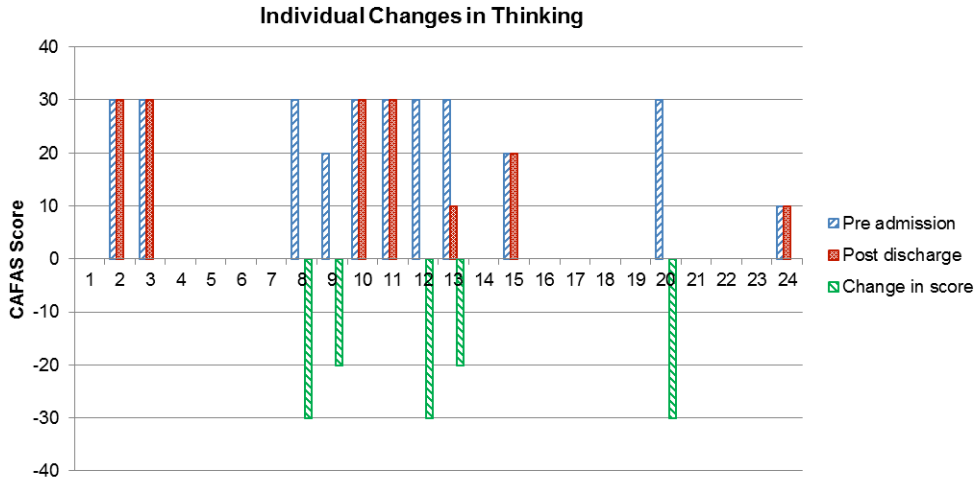



Figure 22: Individual Changes in CAFAS Domain: Thinking

## Appendix B

### Interview Questions

*Complete prior to interview*

Method: _____ Phone

Date: _____ _____ In-Person

Time: _____ Disposition: ___ Completed Interview

___ Unable to complete: _____

Youth's Name: _____

Interviewee: _____ Relationship to Youth: _____

Interviewer: _____

Length of time in RESPOND: _____ Months

Residential Location: _____

Is youth still in RESPOND? _____ Yes _____ No

If youth has left RESPOND, where did youth return to?

_____ Parent/Guardian

_____ Other Family

_____ Foster Parent

_____ Residential Placement

_____ Other

---

**Introduction:**

1. In order to get this started, and for me to get a better understanding of your general experience with RESPOND, please tell me how you would describe the RESPOND program to a friend, if you had to:

2. About how often did you visit /see [name] while he/she is/was in RESPOND?

## Appendix B

3. While in RESPOND, did staff accompany [name] to your home for visits?

4. Did you have unsupported or overnight home visits with [name]?

**Please answer the following questions about the RESPOND process and [name]'s progress while in RESPOND.**

5. Did you fully understand the RESPOND program and what the staff would try to do for [name] prior to his/her entry into the program?

6. When [name] entered RESPOND, what were some of the most important things you wanted to see change or improve for him/her? Some of the most important goals or outcomes?

7. Do you think the RESPOND team understood these priorities? ___ Yes___ No

8. Do you think the team had the same priorities? ___ Yes___ No

9. *(If still in RESPOND, "At this point, have you witnessed…")*

At the conclusion of the RESPOND program, did you witness success in meeting any of these goals?

If yes: Can you give me an example? _____

Do you think this success will continue in the long run?

10. How has [name]'s interaction with family members changed since entering RESPOND?

## Appendix B

11. By the end of RESPOND, was there any improvement in personal hygiene skills or other daily living skills (independently brush teeth, use bathroom, prepare meal, get dressed, etc.)?

    If yes, list 2 examples: 1) _____

    2) _____

**If youth left RESPOND: Did these abilities change after leaving RESPOND?**

12. Did you see an improvement in [name]'s ability to problem solve or follow directions?

**If youth left RESPOND: Did these abilities change after leaving RESPOND?**

13. While [name] was in RESPOND, did you notice any changes in his/her behavior while at school?

14. During this time, did you notice any changes in how much he/she was learning while at school?

15. Was the RESPOND team able to help [name] identify activities that he/she likes to do, that are calming and enjoyable?

    If yes: Can you give me an example? _____

16. Did [name]'s physical health improve?

## Appendix B

17. Was [name]'s diet and nutrition monitored while he/she was in the program?

    a. *If yes:* How did the change in diet affect [name]?

    b. Did [name] continue the diet after leaving RESPOND?

18. What medical/dental services did [name] receive while in RESPOND?

19. Did the treatment team change the medications [name] was taking?

    *If Yes:* What did the change do for [name]?

*[Do you think the new medications are more effective, less effective, or about the same as the previous medications?]*

20. Did the frequency of emotional outbursts change from the beginning to the end of the RESPOND program? How so?

21. Did the frequency of [name] engaging in acts of physical aggression change during this time? How so?

22. Did the RESPOND team help to identify the factors that cause [name] to be aggressive towards him/herself or others?

23. Was the team able to find ways to successfully manage what was upsetting to [name]?

## Appendix B

**If youth left RESPOND:**

24. Talk a little bit about [name]'s transition from RESPOND back into the community.

*If prompting needed:*

Was the family (or provider) fully informed and prepared to handle the discharge plan?

How was collaboration between RESPOND staff and new caregivers, new doctors?

How has [name] adapted to new routine? New home? New people?

Changes in behavior?

25. Did the frequency of emotional outbursts change after leaving RESPOND?

*If it has increased:* How have you (or other caregiver) adapted to these changes?

26. Did the frequency of physically aggressive acts change after leaving RESPOND?

*If it has increased:* How have you (or other caregiver) adapted to these changes?

**If youth still in RESPOND:**

27. Do you have any concerns related to [name]'s transition out of RESPOND?

## Appendix B

**Final Questions:**

28. In your opinion, is [name] currently living in the most appropriate place?

29. Overall, do you think [name] is better off as a result of participating in RESPOND?

30. What do you think worked well in RESPOND?

31. What do you think could have gone better?

32. What was different about your experience with the RESPOND program from other programs /services your child has received?

33. Is there anything else you would like to share with us that we have not already discussed?