



# Annual Monitoring Report

October 1, 2012 – September 30, 2013

## EXECUTIVE SUMMARY

Over the past two years data from many sources indicates DD services and supports in DC are improving. As a result, expectations have been raised and people are less willing to accept excuses for failure. People want a nice place to live, friends to share their lives with; and friendly knowledgeable people to assist where it is needed. Having raised expectations, it is now the responsibility of the Department of Disability Services (DDS) to ensure that, as their website says, “residents with intellectual disabilities receive the services and supports they need to lead self-determined and valued lives in the community.”

Our random monitoring efforts this year concentrated on non-*Evans* class members living at home with family. Overall, the results regarding Service Coordinators were positive; 97% of the people we met reported they know their Service Coordinator, and 95% indicated they had been visited during the year. Just over half the people we met (52%) receive In-Home Supports, and approximately 70% of that group expressed satisfaction with the service. Seventy seven (77%) of the people we met are engaged in some kind of day program or work related activity. Results in the area of meaningful day activity were less positive. For those people receiving center - based supports, we found a current ISP 75% of the time. Of those ISP's 75% contained goals expressed in measurable terms, 62% contained goals based on the person's preferences and choices, and we found 46% of the staff received training on the person's health related needs.

We continue to see improvement with the Incident Management & Enforcement Unit of DDS. Of the 1160 Serious Reportable Incidents recorded in FY 2013, fully 92% were closed on time. As recently as FY 2010, the rate of timely closer was only near 50%. Again this year unplanned trips to the Emergency Room were the largest single category of incident for both class and non-class members. This year there was a significant increase in neglect incidents, but a decrease in abuse. Taken together, unplanned trips to the hospital and neglect accounted for 64% of Serious Reportable Incidents in FY 2013.

Our review of the work done by the DDS Restrictive Control Review Committee, BSPs for non-class members demonstrate some significant weaknesses with providers of mental health and behavioral support services and provider Human Rights Committees (HRC), and also with DDA practices. We also note some areas of improvement within DDA. Enhancement in data collection relating to BSP reviews was made. We also are encouraged by DDA's enhanced effort to review BSPs and improve RCRC that resulted in decreasing the average waiting time between a BSP's development and its review by the Committee. Based on rough DDS estimates shared with Quality Trust, around 750 people are thought to have BSPs with restrictive controls that would require regular RCRC review. Only 424 BSPs were reviewed last year, and only about half of those were for non-class members despite the fact that they constitute around three-fourths of people in the DDA system.

Most of the people receiving services in the District of Columbia are young and have different health profiles than *Evans* class members. Their expectations center on working, and experiencing an integrated and varied social life. There are currently 530 *Evans* class members who are over 50 years old, and for whom life “in the community” began in or around 1989. While these two groups have differences, in so many ways they are also alike. All want and need opportunities outside of segregated day programs and congregate living homes. To engage in those experiences they first need the benefit of coordinated, adequate medical and behavioral health services. Having raised expectations, it is now the responsibility of DDS to ensure the delivery of high quality services and supports to the approximately 2190 people in the DD system in the District of Columbia.

## INTRODUCTION

Like everyone else, people with developmental disabilities want simple things out of life. That is what has been found throughout the nation and it is true in the District of Columbia. We have documented their aspirations in our annual reports since 2008.<sup>1</sup> Until recently the lack of success in creating a coordinated system of DD services in the District of Columbia made attaining those aspirations difficult for many and impossible for some. Over the past two years however, our data indicates DD services and supports in DC are improving. As a result, expectations have been raised and people are less willing to accept excuses for failure. People want a nice place to live, friends to share their lives with; and friendly knowledgeable people to assist where it is needed. They want to spend their time doing things that interest them. And they want jobs, or at least help to gain greater access to life outside the walls of a group home or day program. Having raised expectations, it is the responsibility of the Department of Disability Services (DDS) to ensure that, as their website says, “residents with intellectual disabilities receive the services and supports they need to lead self-determined and valued lives in the community.”<sup>2</sup>

Systems change initiatives, some dating back to 2007, have resulted in DDS creating a fully coordinated multi-disciplinary approach to helping people live lives of dignity and worth. According to their website, they provide direct services, such as outreach and service coordination services. They also develop and manage a provider network delivering community residential, day, vocational, employment and individual and family support services; and they operate a comprehensive quality management program.<sup>3</sup> Having achieved these results they have the obligation to ensure greater accountability among those who provide services and supports.

Expecting your Service Coordinator to create an individualized plan (ISP) detailing who you really are and what you need should now be a given. As should expecting your provider to put in place trained motivated staff to achieve the goals of that plan. There should be no problem making that happen consistently. Help acquiring the skills necessary to find a job with which a person can buy the things they want should be an accepted part of agreeing to choose one

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<sup>1</sup> QUALITY TRUST, Annual Monitoring Report & Data Summary (October 1, 2007 – September 30, 2008), *available at* [http://www.dcqualitytrust.org/documents/2007-08Monitoringreport\\_000.pdf](http://www.dcqualitytrust.org/documents/2007-08Monitoringreport_000.pdf) (last visited Jan. 30, 2014) (hereafter, “Quality Trust 2008 Report”); QUALITY TRUST, Annual Monitoring Report & Data Summary (October 1, 2008–September 30, 2009), *available at* <http://www.dcqualitytrust.org/documents/2008-09Monitoringreport.pdf> (last visited Jan. 30, 2014) (hereafter, “Quality Trust 2009 Report”); QUALITY TRUST, Annual Monitoring Report & Data Summary (October 1, 2009 – September 30, 2010), *available at* <http://www.dcqualitytrust.org/documents/QT2010MonitoringReport.pdf> (last visited Jan. 30, 2014) (hereafter, “Quality Trust 2010 Report”); QUALITY TRUST, Annual Monitoring Report & Data Summary (October 1, 2010 – September 30, 2011), *available at* <http://www.dcqualitytrust.org/documents/AnnualMonitoringReport2011final2812.pdf> (last visited Jan. 30, 2014) (hereafter, “Quality Trust 2011 Report”); QUALITY TRUST, Annual Monitoring Report & Data Summary (October 1, 2010 – September 30, 2011), *available at* [http://www.dcqualitytrust.org/documents/QTMonitoringAnnualReportFINAL\\_000.pdf](http://www.dcqualitytrust.org/documents/QTMonitoringAnnualReportFINAL_000.pdf) (last visited Jan. 30, 2014) (hereafter, “Quality Trust 2012 Report”).

<sup>2</sup> D.C. DEPT. ON DISABILITIES SERVICES (hereafter, “DDS”), Who We Are, *available at* <http://dc.gov/DC/DDS/About+DDS/Who+We+are/Department+on+Disability+Services> (last visited, Jan. 30, 2014).

<sup>3</sup> See *id.*

provider over another. But as we know achieving these expectations is more difficult to realize than it is to envision.

When there is a failure to carry out these mandates there is now an expectation that corrective action will be taken, and improvements will follow. Failures of both commission and omission continue to occur. According to the Incident Management & Enforcement Unit of DDS, just less than 60% (59.23%, or 186 of 314) of incidents involving allegations of neglect were substantiated. What are we to think about a system when almost 6 in 10 reports of neglect are confirmed? On one hand, it is a positive sign that providers can identify and report instances of neglect when they occur. From a different perspective, we need to ask hard questions about the frequency with which these situations are reported. These findings demonstrate that the government has developed the ability to collect and analyze data regarding critical performance indicators. We continue to grapple with what is a reasonable expectation for DDS to sanction, and if necessary remove providers when performance problems persist. As we have noted in prior reports, the government's ability to ensure effective or even adequately safe services and remediate problems is only as effective as the pool of providers with whom they contract.<sup>4</sup>

At Quality Trust our efforts to support people with disabilities to be seen as more than the labels and limits placed on them are at the heart of our monitoring and lay and legal advocacy. We continue to see a bias toward the use of substituted decision making strategies such as guardianship in practice<sup>5</sup> and will be collecting additional data on this in the coming year. Quality Trust has provided individualized advice and guidance on their rights and alternatives to guardianship to over 70 District of Columbia residents, helping some avoid guardianship in favor of Supported Decision-Making and other less restrictive alternatives for decision making assistance. We are also actively working to train people with disabilities, advocates and attorneys on capacity, Supported Decision-Making and other alternatives to guardianship.

Having completed approximately 800 monitoring reviews of non *Evans* class members who live outside of their family home during the past five years, we decided this year to turn our attention to those non class members who reside with family. While much attention has been paid to members of the class action litigation, very little is known about the group of non class members living at home with family. Our goal was to better understand the extent to which the services they receive help them in their day to day lives. Do they have the services they need? Do they know their DDS Service Coordinators? Do they spend their day engaged in meaningful activities? Are their transportation providers reliable? Overall our findings were positive. As with any work of this kind we also encountered people needing services they didn't have, or whose services were not meeting their needs. In those cases we made recommendations for improvement to the Service Coordinator or the providers responsible for their services and supports. In a limited number of situations we made referrals to our advocates or attorneys for targeted assistance.

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<sup>4</sup> See, e.g., QUALITY TRUST 2010 REPORT at 19; QUALITY TRUST 2012 REPORT at 2.

<sup>5</sup> See D.C. DEPT. ON DISABILITIES SERVICES, Annual Plan of the Department on Disability Services to the Council of the District of Columbia on Substitute Decision Makers and Psychotropic Medication for People with Developmental Disabilities (for Fiscal Year 2014), at 4 (November 1, 2013) (on file with the author) (Of the 1,547 of the 2,196 people with intellectual and developmental disabilities DDS serve – 70% – have a guardian or legally authorized substitute decision-maker).

2013 also marked our first experience developing the tools and processes we will use to monitor vacated Court Orders in the Evans case going forward. The 2010 Update of the 2001 Plan for Compliance contained nine goal areas containing 70 individual criteria requiring completion. The case has focused on these nine goal areas over the past three years. Three of the nine goal areas (A. 4, staff training, C. Personal Possessions, and F. Adequate Budget) have been fully completed. Monitoring in these areas is now the responsibility of Quality Trust. A number of individual criteria within the remaining six goals have been completed, but additional criteria in each of these goal areas remain outstanding. Those remaining areas are the focus of the case this year.

We continue to receive, review, and analyze all of the Serious Reportable Incidents reported to DDS and the subsequent investigations. Our process includes an immediate review of incidents for non-*Evans* class members to ensure action is taken when needed as well as review of the content and comprehensiveness of non-class member investigation reports. While we receive SRIs and investigations for both class and non-class members, our review and analysis of data in this report focuses primarily on non-*Evans* class members as the Court Monitor reports on the status for members of the class.

#### METHODOLOGY

This report focuses primarily on the services and supports provided to non-*Evans* class members consistent with our mandate while the *Evans* class action is still ongoing. We have again based our random review process on “Sampling, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs.”<sup>6</sup> We used a simple random sample drawn from a list provided by DDS Quality Management staff. We used Random Integer Generator to produce a True Random Number sequence which we then matched to the corresponding names in the information provided by DDS. We interviewed 169 people and their families while completing this work. That number represents a sample size of 25% (169 of 698).

For our initial review activities regarding the areas already certified in the 2010 Evans Plan around staff training and protection of personal funds, we completed 34 reviews of class members. Again we used a simple random sample drawn from a list of approximately 160 class members not previously reviewed by the Court Monitor’s office. That number represents a sample size of 22% (34 of 160).

Additionally, Quality Trust’s Monitoring unit received reviewed and analyzed incident management data for non-class members. Again, the data in this report (except where specifically indicated) involves non *Evans* class members only. We triaged all of the 756 Serious Reportable Incidents involving non class members. Having reviewed the work product of the Incident Management & Enforcement Unit (IMEU) of DDS for close to 10 years now, the data now reveals that the quality of the work has substantially increased. For that reason we

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<sup>6</sup> Ruth Freedman & Sarah Taub, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs (Human Services Research Institute & Medstat Group, Inc. dev., National Quality Contractor 2006).h Institute & Medstat Group, Inc. dev., National Quality Contractor 2006).

completed a statistically significant sample of 308 investigations rather than review of all investigations.

### NATURAL HOME REVIEW

Data in this section of the report is drawn from interviews with 169 non class members who live at home with family. Since the people in the sample this year did not live in traditional provider settings, we made special efforts to inform them and their families that participation in the review was completely voluntary and would in no way affect current or future services. Only one person who agreed to participate with us declined to be interviewed. In that case we respected their preference and ended the review. We did however encounter a significant number of people (approximately 60) who declined to participate. Another significant group (Approximately 30) either did not return multiple messages or for whom working phone numbers could not be confirmed. In some other situations we learned that people had moved out of state, or into congregate living arrangements during the period of the review. Due to all of these factors, our rate of non-participation was much higher than in previous years.

Overall the people we met live in supportive family arrangements. As a group they are even younger than the non class members we have met who live outside the family home. Most of the people we met said their services meet their needs. For those people who attended some kind of congregate day program activity, our findings related to training of staff (46% had documentation of training related to the person's health needs), and presence of a current ISP (75% available at the day program) were poor. Just over half the people we met (52%) had some type of In-Home Services, and 70% reporting being satisfied with those services. The most discussed need for this group is meaningful employment or some other type of day activity outside of the home. Of the people engaged in some type of day activity 23% reported they have a job. Of the people who were not currently working, most expressed a desire to get some kind of job. The people we met who do work said they would like more hours. In all of these situations involving employment related challenges people look to either their Service Coordinator or the Department of Rehabilitative Services for assistance with employment.

Several of the family members we met asked questions of us which revealed a lack of awareness of the services and supports available to them. In those cases we pointed out the role of their Service Coordinator, and followed up to ensure that information was shared, and connections made. In the few instances where a more productive relationship with their Service Coordinator was desired we assisted to ensure that more consistent follow-up occurred or a new Coordinator be considered.

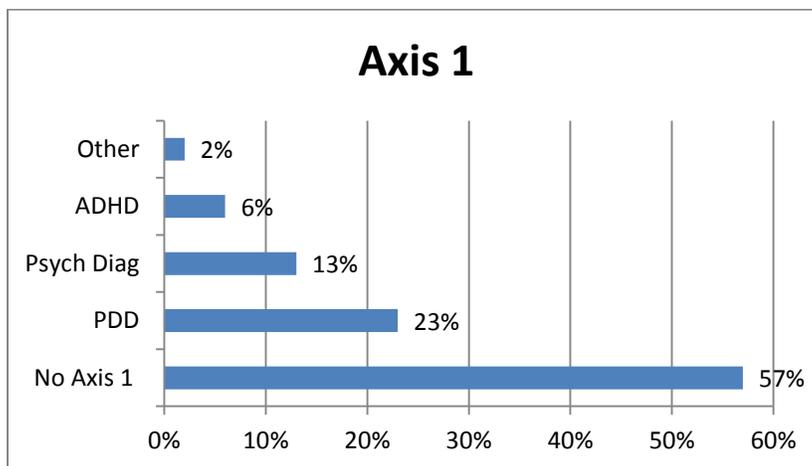
## DEMOGRAPHICS

According to Developmental Disabilities Administration, there are now approximately 1635 non *Evans* class members receiving services and supports. Of that total, approximately 685 live at home with family. Within our group of 169 people we found:

- People between the ages of 21-30 were the largest group at 45.6%
- 92.3% of this group are between the ages of 21-50
- 21-50 year olds living in congregate settings has tended to be around 80%
- We met 13 people (8%) who are between the ages of 51-70 years of age
- No one was over the age of 70 years of age

The data regarding the presence of an Axis I diagnosis is interesting. We found that:

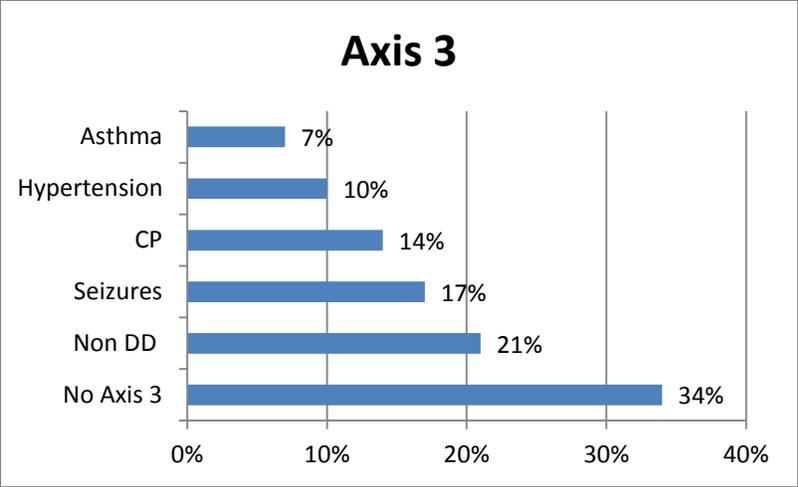
- 57% have no Axis I diagnosis
- 23% have a diagnosis of Pervasive Developmental Disorder
- 13% have a psychiatric diagnosis of some kind
- 6% have a diagnosis of ADHD
- 1% have ill-defined diagnoses which we labeled "other"



**\*A note to the reader. The statistics in the following sections do not always total 100% because several people had more than one diagnosis.**

The data regarding the presence of an Axis III diagnosis is similarly interesting. The following health issues were found:

- 34% have no Axis III diagnosis
- 21% have various non-serious diagnoses such as seasonal allergies, anemia, & constipation
- 17% have Seizure Disorders
- 14% have Cerebral Palsy
- 10% have Hypertension
- 7% have Asthma

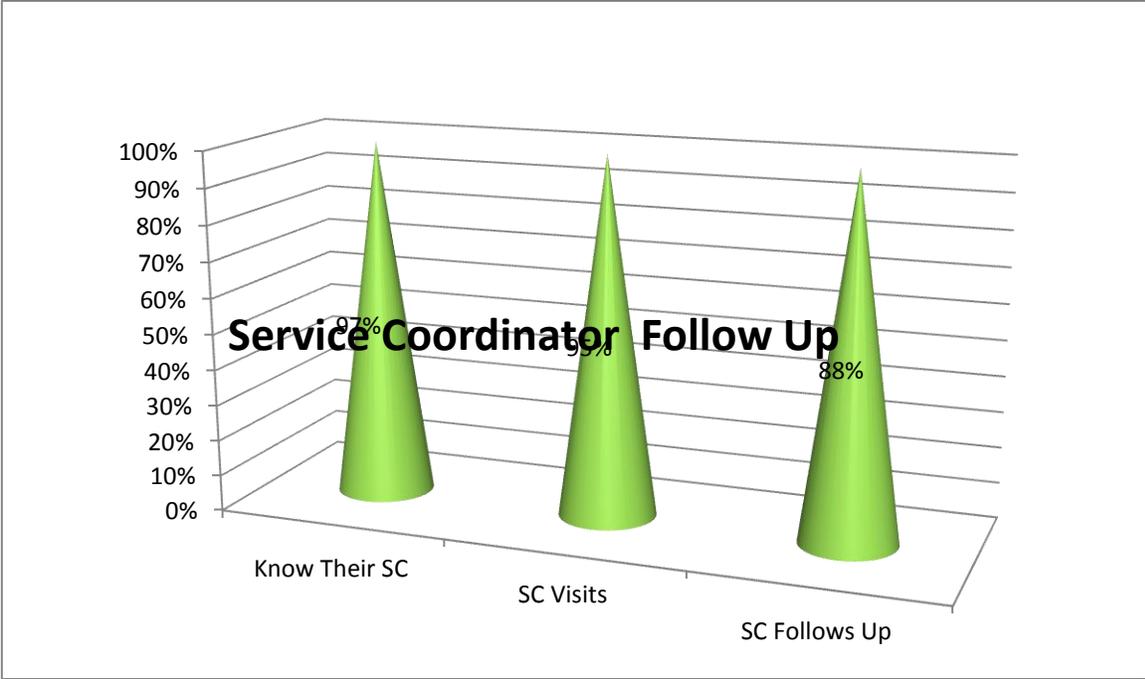


- 81% of the people did not have a Legal Guardian of any kind. The remaining 19% had a Guardian appointed at some point in their lives.

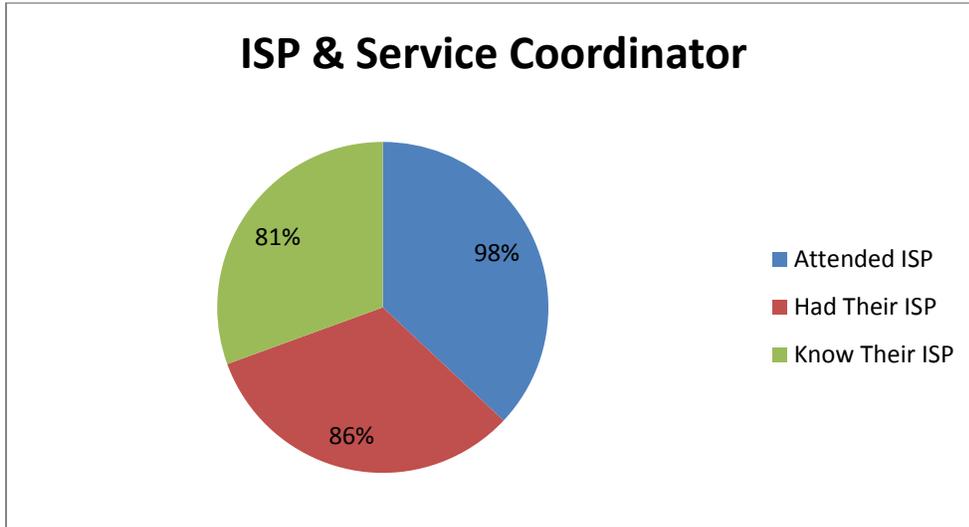
Personal Interview

Interviewing people with disabilities is the heart of our approach at Quality Trust. Whether through our advocacy, monitoring, or legal advocacy our focus is always on meeting with and learning from people with disabilities. We want to know who they are, what they want, and how they can access the supports they need to create lives that are personally meaningful. It is through this process that we come to understand their challenges. The personal interview was the heart of this year’s monitoring tool. Through interacting with the people we met and their families we hoped to understand what was and was not working for them as they live their lived day by day. The following data is drawn from those interviews:

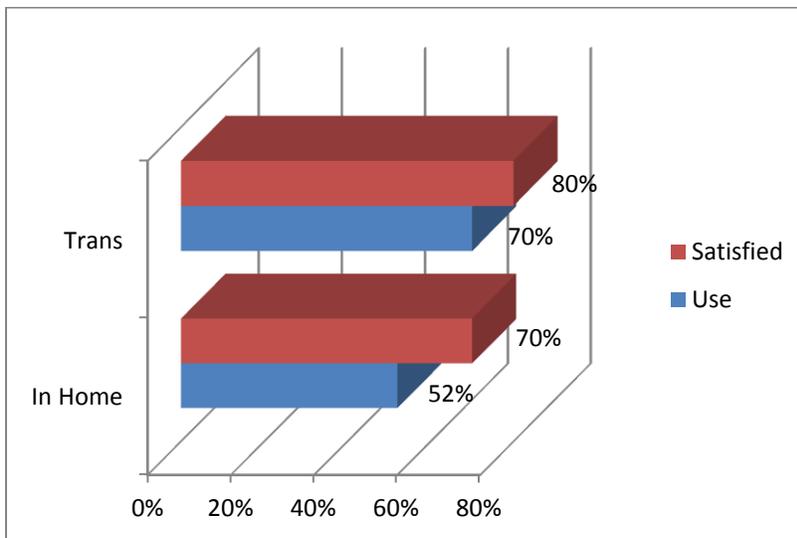
- 79% of the people we met were able to answer our questions with little or no support from a family member.



- 97% report knowing their DDS Service Coordinator
- 95% report that their Service Coordinator had visited them at least once during the year
- 88% report that their Service Coordinator follows up on issues important to them



- 98% report attending their ISP meeting, and 92% reported they either had no concerns or the concerns were adequately addressed
- 86% had a current copy of their ISP in the home
- 81% report that the ISP had been explained to them, and they knew its contents



- 70% report receiving transportation services

- 80% report that their transportation provider picked them up and dropped them off as scheduled
- 52% report they receive In-Home supports, and
- 70% are satisfied with those services
- 57% report they have goals that are not currently being realized. Not everyone was willing to share their goals with us, but of those who did:
  - 18% would like a job, or opportunity to volunteer somewhere
  - 11% wanted a number of individual outcomes such as to lose weight, be more active in their communities, and see their friends more than they currently do
  - 8% would like to increase their skills so that they could get a job, or a better job
  - 7% want to attend a day program that would match their interests
  - 6% want more independence-especially to move into their own home or apartment, and;
  - 4% want to travel more than they currently do

For people who do attend a day program we asked a series of questions to gauge their interest in and satisfaction with that program or activity. Specifically:

- 77% had either a day program or job or volunteering opportunity of some kind. Of that group:
  - 42% engage in some kind of Day Habilitation
  - 18% participate in Pre-Vocational activities and;
  - 15% attend Day Treatment programs
  - 12% report they are receiving Supported Employment supports
  - 11% report they are competitively employed
  - 86% of those attending a facility based service reported it was accessible to their needs

For everyone except those competitively employed:

- a current ISP was located 75% of the time
- There was a vocational assessment available for 49% of those receiving day program supports
- With the exception of those competitively employed, we found evidence that 46% of staff received training on the person's health related needs
- 62% of the day program goals were developed based on the person's interests and strengths
- 75% of the day program related goals were written in measurable terms
- We found evidence that data on goals was being collected per the ISP 75% of the time
- 84% of the staff was able to describe the person's likes and dislikes
- Day Program staff report that activities are integrated for 76% of the people we met

*We judge the actual number of people involved in integrated activities to be significantly lower as the types of activities cited involved as many as six people with disabilities and their support*

*staff traveling together to places like libraries, malls, fast food restaurants, etc. In fact several staff described activities taking place in the home as “integrated” because they revolved around role playing activities such as making change that are to be used once activities in the community commence. Clearly there is a significant need for more training on the part of day program leadership reading the definition of least restrictive/most integrated services and supports.*

- 23% report they have a job

## Conclusions

Overall there are 2193 people receiving supports funded through the Developmental Disabilities Administration. Approximately 850 of them live at home with family – 685 are non-class members. The people we met this year are young, almost exclusively African American, and live in all wards of the city. Most did not have complex health and or behavioral health needs. The overwhelming majority reported that they had met their DDS Service Coordinator, and that person helps them when problems arise. The three services they need most are: dependable In-Home supports, reliable transportation services, and meaningful day time activities; preferably involving employment.

As we have commented in our previous reports, the vast majority of people we meet are young.<sup>7</sup> The group of people we met this year is even younger than those in previous years. This year 92% were between the ages of 21-50. During the past few years, reviewing people living outside of their family home the percentage tended to remain steady at around 80%. In previous reports we noted that the younger people we met had never been institutionalized and are looking for different kinds of services than those of prior generations.<sup>8</sup> Similarly again, the people we met this year have never lived in congregate living arrangements away from the familiarity of life long family relationships and the expectations they have for DDS funded services and supports are uniquely their own.

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<sup>7</sup> See QUALITY TRUST 2008 REPORT at 4; QUALITY TRUST 2009 REPORT at 4; QUALITY TRUST 2010 REPORT at 3-4; QUALITY TRUST 2011 REPORT at 3; QUALITY TRUST 2012 REPORT at 7.

<sup>8</sup> See QUALITY TRUST 2010 REPORT at 4; QUALITY TRUST 2011 REPORT at 3; QUALITY TRUST 2012 REPORT at 7.

## Review of Behavior Support Plans

During the 2013 fiscal year, Quality Trust served on the DDA's Human Rights Advisory Committee (HRAC) and the Restrictive Control Review Committee (RCRC) (collectively "Committees"). Throughout the year, Quality Trust, in its monitoring capacity, also received copies of the Committees' minutes on a monthly basis.<sup>9</sup>

Under current DDA policy, all Behavior Support Plans (BSPs) utilizing restrictive controls or involving the use of psychotropic medications must be reviewed and approved by RCRC.<sup>10</sup> Restrictive controls include any device, procedure, protocol, or action that restricts, limits, or otherwise negatively impacts a person's freedom of movement; control over his or her own body; or access to anything that would typically be available to people in the community, including privacy.<sup>11</sup> Psychotropic medications are medication prescribed specifically to stabilize or improve mood, mental status, or behavior.<sup>12</sup>

### Findings

Over the past fiscal year, the Committees reviewed a total of 621 BSPs for 424 people receiving services and supports from DDA.<sup>13</sup> This represents a slight (around 1%) increase in Committee-reviewed BSPs, as compared to the findings in our prior year's report.<sup>14</sup> We will focus on the subset of plans for non-class members – of which there were a total of 329 BSPs for 235 people.

- Evans versus Non-Class Members -- Of the 621 BSPs reviewed by the Committees during the year, more than half (53%; 329/621) were for non-class members. Taking into account that each person can have more than one BSP reviewed by the Committees per year, we also found that more than half (55%; 235/424) of the people whose plans were reviewed were non-class members. This departs from our findings

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<sup>9</sup> DDS, RCRC Procedure, § 3.F.12 (effective Sept. 3, 2013), available at [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/RCRC%20Procedure%2008-9-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/RCRC%20Procedure%2008-9-2013.pdf) (last visited Feb. 3, 2014) (hereafter, "DDS Sept. 2013 RCRC Procedure").

<sup>10</sup> See *id.* at § 3.A.1 and DDS, BSP Safeguards & Oversight Procedure at § 3.C.1.d (effective Sept. 3, 2013), available at [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/BSP%20Oversight%20Procedure%2008-9-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/BSP%20Oversight%20Procedure%2008-9-2013.pdf) (last visited Feb. 3, 2014) (hereafter, "Sept. 2013 DDS BSP Oversight Procedure") and Sept. 2013 DDS RCRC Procedure at § 3.F.12; see also DDS Behavior Support Policy at § 4.G (eff. August 2, 2011 to September 2, 2013) (on file with author) (prior procedure requiring HRAC or RCRC to review BSPs with restrictive controls).

<sup>11</sup> See DDS, Human Rights Definitions (effective Sept. 3, 2013), available at [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/Human%20Rights%20Definitions%2008-9-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/Human%20Rights%20Definitions%2008-9-2013.pdf) (last visited Feb. 3, 2014) (hereafter, "DDS Sept. 2013 Human Rights Definitions") and footnote 4.

<sup>12</sup> See DDS Sept 2013 Human Rights Definitions; see also DDS Definition Appendix, available at <https://sites.google.com/a/dc.gov/dds-definitions-appendix/> (last visited Feb. 3, 2014) (defining "Restrictive Control" to include, e.g., psychotropic medication).

<sup>13</sup> Some plans that the committees reject or approve with modification come back to the committees to be reviewed after modifications are made.

<sup>14</sup> See Quality Trust 2012 Report at 11 (noting that Quality Trust, through its participation in HRAC and RCRC, reviewed a total of 615 plans in fiscal year 2012).

last year, when the majority of BSPs reviewed by the Committees were for Evans class members.<sup>15</sup>

- Waiting Times for Committee Review -- We again noted a wide range of waiting times for non-class members BSPs to be reviewed by the Committees after their development, with the greatest being 490 days and the shortest time being 2 days. Part of the reason for some of the shorter timeframes was that a Committee rejected a previous version of the BSP, with the revised plan later coming back and being tracked from the date of revision, rather than the original plan date. The average waiting time for those BSPs identified for Committee review was 128 days – over 4 months -- from the time the plan was written until the date of review. This represented a 22% shorter average waiting time than we found last year.<sup>16</sup>
- Most BSPs Not Approved as Written by the Committees -- Of the BSPs reviewed for non-class members, only 12% (41/329) were approved by the Committees as written. This rate is consistent with our findings last year.<sup>17</sup> Another 38% (126/329) were approved by the Committees with qualifications, which included limitations on the length of time of the qualified approval. The Committees rejected 42% (138/329) of the BSPs and sent them back with suggestions for a rewrite. Of those rejected BSPs, we learned that DDS QMD overruled the Committee's decisions in at least 5 instances, deciding to approve with qualifications instead. The Committees deferred making a determination on 7% (24/329) of the BSPs, because they did not have all the information needed for the review.
- Statistics on Committee Recommendations -- Our review found a number of concerns with proposed BSPs for non-class members:
  - 47% (154/329) of the BSPs had components that were too negative or restrictive.
  - There were issues with data and/or data tracking in 47% (154/329) of the BSPs. BSPs generally must include a year's worth of data on a person's target behaviors,<sup>18</sup> so that there can be an assessment of the effectiveness of interventions, the continued justification of any restrictive controls, and the progress a person and his or her providers are making in achieving behavioral goals.

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<sup>15</sup> See *id.* (finding that, of the 615 BSPs reviewed by RCRC and/or HRAC during Fiscal Year 2012, 55% were for Evans class members).

<sup>16</sup> See *id.* at 12 (finding the average wait time for non-class members' BSP was 165 days).

<sup>17</sup> See *id.* (finding that 11% of the BSPs reviewed for non-class members were approved as written).

<sup>18</sup> See DDS, BSP Requirements Procedure at § 3.C.6 (effective Sept. 3, 2013), available at [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/BSP%20Requirements%20Procedure%20Draft%208-9-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/BSP%20Requirements%20Procedure%20Draft%208-9-2013.pdf) (last visited Feb. 3, 2014) (hereafter, "DDS Sept. 2013 BSP Requirements Procedure"); see also DDS BSP Procedure at § 3.B.14 & 16 (effective Aug. 1, 2011 to Sept. 2, 2013) (on file with the author) (hereafter, "Prior DDS BSP Procedure") and DDS BSP Template at § 6 (effective Aug. 1, 2011 to Sept. 2, 2013)

- 46% (151/329) of the BSPs had no fade plan or an inadequate fade plan. BSPs must describe a clear plan for reducing, fading, or eliminating the use of restrictive control procedures.<sup>19</sup> This represents a 20% increase from last year.<sup>20</sup>
- There was a concern about the prescribed medication(s) in 37% (121/329) of the BSPs.
- There was a concern with the Axis I or mental health diagnosis in 24% (79/329) of the BSPs. Under DDA Policy, psychotropic medications must be linked to a corresponding mental health diagnosis in order to not be considered a prohibited chemical restraint.<sup>21</sup>
- In 22% (73/329) of the BSPs, there was an inadequate functional assessment or concerns about the suggested proactive strategies that would be used to prevent the behavior from occurring. BSPs must include a summary of the hypothesized function of each target behavior<sup>22</sup> and identify and promote alternative replacement skills and competencies that the person can use instead that will serve that same function.<sup>23</sup> This suggests BSP developers have improved in this area since last year, when 41% of the BSPs for non-class members were identified as having this concern.<sup>24</sup>
- 7% (24/329) of the BSPs had no crisis plan or an inadequate crisis plan. BSPs must describe the specific procedures for supporting people during crisis events.<sup>25</sup>

## Conclusions

A look back at the BSPs for non-class members taken as a whole and the review process demonstrate some significant weaknesses with providers of mental health and behavioral support services and provider Human Rights Committees (HRC), and with DDA practices. We also note some encouraging areas of improvement within DDA.

Over the last fiscal year, we know that DDS has made great strides in terms of data collection relating to BSP reviews. While we are pleased that the workload of the Committees includes a greater percentage of BSPs for non-class members than last year, we remain concerned that

<sup>19</sup> See DDS Sept. 2013 BSP Requirements Procedure at p. 6-7, § C.12.a & f; see also Prior DDS BSP Procedure at § 3.B.14.

<sup>20</sup> See Quality Trust 2012 Report at 13 (finding that 26% of the BSPs for non-class members that the Committees reviewed had no fade plan or an inadequate fade plan).

<sup>21</sup> See DDS Human Rights Policy at § 6.3.e.viii (effective Sept. 3, 2013), available at [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/Human%20Rights%20Policy%208-9-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/III%20Health%20and%20Wellness/Human%20Rights%20Policy%208-9-2013.pdf) (last visited Feb. 3, 2014) (prohibiting chemical restraint) and DDS Sept. 2013 Human Rights Definitions (defining chemical restraint); see also DDS Human Rights Policy at § 6.9.s (effective Aug. 1, 2011 to Sept. 2, 2013) (on file with the author) (prior human rights policy).

<sup>22</sup> See DDS Sept. 2013 BSP Requirements Procedure at § 3.C.7; see also Prior DDS BSP Procedure at § 3.B.8.

<sup>23</sup> See DDS Sept. 2013 BSP Requirements Procedure at § 3.C.9; see also Prior DDS BSP Procedure at § 3.B.10.

<sup>24</sup> See Quality Trust 2012 Report at 13.

<sup>25</sup> See DDS Sept. 2013 BSP Requirements Procedure at § 3.C.11; see also Prior DDS BSP Procedure at § 3.B.12.

not all are having their BSPs reviewed in a timely manner. Based on rough DDS estimates shared with Quality Trust, around 750 people are thought to have BSPs with restrictive controls that would require regular RCRC review. The fact that only 424 BSPs were reviewed last year and only about half of those were for non-class members lends credence to our concerns, when our demographic data indicates they constitute around three-fourths of people in the DDA system. As the District strives to meet Evans compliance criteria, we know that more scrutiny is and will continue to be placed on RCRC review of class members' BSPs. We caution DDA to avoid disadvantaging the ever-growing population of people who are not part of that class.

We also are encouraged by DDA's enhanced effort to review BSPs and improve RCRC operations, including increasing the frequency of RCRC meetings to at least every week beginning in March 2013, filling an additional Rights and Advocacy Specialist position in July 2013, and decreasing the average waiting time between a BSP's development and its review by the Committee. However, we note that, despite these efforts, there was only a very slight increase in the total number of BSPs reviewed by the Committees this year, as compared to last year. There may be a variety of reasons for this, including decisions by people's Support Teams to discontinue BSPs as psychotropic medications are faded or to recommend the person use exemption or opt out options available under DDA procedures. Regardless, it raises questions about the current capacity of RCRC to meet its workload. We recommend DDA continue its concerted effort to recruit new members – particularly those external to DDS -- and mobilize additional RCRCs to meet the demand.

Unfortunately, the vast majority of non-class member plans reviewed by the Committees last year continued to not be approved as written. We do find it encouraging that DDA and its Committees do not approve insufficient or inappropriate BSPs. We hope that RCRC's reviews will remain as rigorous in promoting human rights under DDS's newly revised policies and procedures, which went into effect on September 3, 2013. However, the above statistics continue to raise concerns regarding the competencies of current BSP developers, as well as provider HRCs that review and approve plans before Committee review. Further training of and outreach to both should be a priority of DDS. While our findings suggest that BSP developers may be getting better at conducting functional assessments, more improvement is needed in, for example, their coordination with psychiatrists on appropriate and meaningful fade plans for restrictions. DDS also must be prepared to take action against providers, where needed, to create financial and other disincentives, so that providers will push the BSP developers they pay to develop high-quality BSPs that meet procedural requirements and professional standards and seek DDS technical assistance where needed. We know that DDS has hired new psychologists who are primarily focusing on improving the quality of Evans class members BSPs and that different criteria relating to supporting documentation are now being applied to RCRC review of those plans – which suggests the very bifurcated system we have we have pushed DDS to avoid. Promotion of high quality standards in BSPs need to occur across the DDS system, not only for Evans class members.

INCIDENTS AND INVESTIGATIONS

There were a total of 1160 Serious Reportable Incidents filed in FY 2013. This number reflects 404 incidents involving *Evans* class members, and 756 involving non class members. During the previous fiscal year 1096 incidents were reported. This marks an increase of 64 or 5.8% from last year.

Incident Type	NCM		CM	
	FY 12	FY 13	FY 12	FY 13
<b><i>Emergency Inpatient Hospitalization/ Unplanned Emergency Hospitalization</i></b>	230	257* EIH-189 UEIH-68	179	167* EIH-107 UEIH-60
<b><i>Inappropriate Use of Restraints</i></b>	3	3	1	0
<b><i>Missing Person</i></b>	86	67	3	3
<b><i>Serious Medication Error</i></b>	8	7	4	3
<b><i>Suicide Attempt or Threat</i></b>	6	7	0	1
<b><i>Allegation of Abuse</i></b>	190	153	65	46
<b><i>Death</i></b>	16	14	21	20
<b><i>Neglect</i></b>	143	190	70	124
<b><i>Serious Physical Injury</i></b>	42	44	29	28
<b><i>Exploitation</i></b>	N/A	8*	N/A	8*
<b><i>Other</i></b>	N/A	6*	N/A	4*
<b><i>Total</i></b>	724	756	372	404

\* (the definition for emergency visits to the hospital was changed from Emergency Inpatient Hospitalization to Unplanned Emergency Inpatient Hospitalization with the new policy which took effect on June 1, 2013)

Some significant findings related to incidents this year are:

- As it has every year since 2008, unplanned trips to the ER was the single largest category of incident (424 of 1160, or 36.5%)
- Within that category, the number rose for non-class members, but fell for class members
- Use of restraints, Suicide threat or attempt, Serious Physical Injury, and Death all remained consistent with previous years for both class and non-class members

- Allegations of abuse dropped for both groups, but the drop was greater for non-class members
- Allegations of neglect rose dramatically for both groups, more than doubling for class members

Each Serious Reportable Incident is investigated by the IMEU. Beginning in the middle of last fiscal year, every unplanned trip to the emergency room was investigated to determine whether or not abuse or neglect played a role in the hospitalization. This year was our first opportunity to analyze a full year of data in this area.

Findings this year regarding substantiation of neglect, abuse, and emergency visits to the hospital were noteworthy.

- There were 190 allegations of neglect involving non-class members - 112 of which were substantiated. That is a rate of 59%
- The numbers for *Evans* class members were higher (74 confirmed of 112 total incidents, 66%)
- For abuse, the numbers were: (59 of 153 substantiated for non-class members or 39%), and (22 of 46 for class members or 48%)

When the same analysis is applied to incidents involving unplanned trips to the emergency room though, an almost exactly inverse result is found.

- For non-class members: 17 of 257 unplanned trips to the hospital involving non-class members were substantiated as being caused by neglect (6.6%)
- For class members the numbers were: 12 of 147 (8.1%)

### Conclusion

We found a significant difference in the number of substantiated neglect between medical and non-medical issues. Substantiated neglect rates of between 39-66% for non-medical related issues were noted, while substantiated neglect involving medical supports was only 6-8%. We have no explanation for this. Unplanned trips to the hospital were the single largest category of incident (424). This year the next largest category was neglect (190 non-class and 124 class member for a total of 314 incidents). Both of these categories taken together accounted for 64% (738 of 1161) of all incidents reported in FY 2013. In the context of the following analysis of unplanned trips to the hospital and deaths completed by our Health Care Monitor, the above information is puzzling, and we believe this data is significant and recommend that DDS look further into any deeper causal connections or explanations.

## A Closer Look at Health and Health Care Issues

A further review of hospitalizations was conducted by the Monitoring team under the guidance and leadership of Quality Trust's Health Monitoring Coordinator (HCM) Kim Johnston, PhD. DNP, MSN, RN, CDDN, consistent with our role as advocates for improved health care access and oversight for people with I/DD. Our efforts focused on collecting data/evidence to apply to the process of promoting best practice in IDD nursing in the District of Columbia.<sup>26</sup> The Health Monitoring Coordinator reviewed Serious Reportable Incidents (SRI) recorded in the DDS database involving Emergency Inpatient Hospitalization (EIH) and/or Unplanned Emergency Inpatient Hospitalizations (UEIH) for fiscal year 2013.

This review revealed a total of 756 reported SRI for non-*Evans* class members (NCM) in FY 2013, 257 (34%) of which were unplanned/emergency admissions to an acute hospital or psychiatric facility. A total of 14 people expired as a result of their illnesses. This made a total sample size of 243 or 11.2% of the total population of approximately 2163 in services.

The 243 triaged SRIs met the written criteria for Serious Reportable Incidents established through DDS' Reportable Incident Definitions published June 1, 2013, and available for review on their website.<sup>27</sup> Of note, eight people in the sample accounted for a total of 45 SRI (ranging from 4 to 7 incidents per person, or 17% of the entire population).

The Health care Monitor reviewed a total of 194 Unplanned Emergency Inpatient Hospitalizations (UEIH) for medical needs and 53 UEIH related to psychiatric needs (247).

Consistent with national trends,<sup>28</sup> the majority of the medical hospitalizations (194 total) were related to pneumonia, aspiration, and respiratory infections (38 or 20%), constipation or fecal impaction (8 or .04%) 5 incidences (.025%) of bowel obstruction, (three of the admissions for one individual), urinary tract infections (UTI) (14 or .07%), 10 admissions diagnoses with sepsis (.04%) and 24 (0.12%) admissions with seizures. The preceding diagnoses account for 99 of the 194 admissions or almost half of the total all medical based admissions.

In addition, thirty-six (0.18 %) of the emergency medical admissions were related to the following sequelae: vomiting, dehydration, hypotension, mental status changes, bradycardia or tachycardia, syncope, and cardiac changes.

This information is significant and calls for further investigation and follow-up to determine the length of time symptoms were present prior to admission and whether or not primary care providers were consulted regarding symptoms prior to the admission. One would expect Service Coordination and Health & Wellness staff from DDS to be following up on this data from providers to promote best practice. One example would be an examination regarding whether

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<sup>26</sup> See, e.g., Ronda Hughes & Mary Blegen, *Patient Safety & Quality: An Evidence-Based Handbook for Nurses*, Chapter 37, Medication Administration Safety (Ronda G. Hues ed., Agency for Healthcare Research & Quality 2008), available at <http://www.ncbi.nlm.nih.gov/books/NBK2656> (last visited Jan. 30, 2014).

<sup>27</sup> See DDS, Reportable Incident Definitions (June 1, 2013), available at [http://www.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/IV%20Quality%20Management/Reportable%20Incident%20Definitions%20Effective%206-1-2013.pdf](http://www.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policies-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/IV%20Quality%20Management/Reportable%20Incident%20Definitions%20Effective%206-1-2013.pdf) (last visited Jan. 30, 2014).

<sup>28</sup> CARE PLANNING AND DELIVERY IN INTELLECTUAL DISABILITIES NURSING (Malden, MA: Blackwell) (Bob Gates ed., 2006).

or not follow-up had occurred in the 8 people admitted to hospital with constipation/impaction to better understand if data had been collected on bowel movements prior to the crisis. It is not enough that the RNs include this diagnosis in the Healthcare Management Plan (HCMP); the plan should be continuously revised and updated to reflect current needs and status. The use of registered nurses by providers as a “first line of defense” is imperative to a successful plan to decrease the number of UEIH in an already vulnerable population. The provider agency RN’s must clearly understand their responsibilities related to physical assessment, coordination of care, and training of unlicensed assistive personnel in the topics of recognizing changes in health status specific to that particular individual. Until these changes are put into place, people with I/DD in the District of Columbia DC will continue to suffer from unnecessary hospital admissions.

In a related but nonscientific review, the Health Care Coordinator reviewed several mealtime protocols for people diagnosed with dysphagia - a risk for aspiration- that could not be termed “person centered or person specific”. To promote best-practice,<sup>29</sup> the symptoms of choking/aspiration must be described by symptoms that the person displays; e.g. “John coughs, sneezes, and has watery eyes when he is aspirating”. It is not best practice to list general signs of aspiration for all individuals as coughing/choking/gagging (before, during, or after meals) /excessive throat clearing/wet gurgled vocal quality/watery eyes, and vomiting. Many people suffer from “silent aspiration” or movement of a liquid or solid bolus into the trachea below the vocal cords, without clinical signs such as coughing, choking, color change, or change in respirations. All care and treatment provided must be individualized if we expect to improve conditions for those people completely reliant on professional staff for their nutrition, and in deed, for their lives.

For the most part, the majority of the 260 SRIs had adequate follow-up by Service Coordination with documentation through MCIS notes into the end of the fiscal year. In most cases there were at least one note recognizing the incident and one note documenting a discharge meeting. There were however, thirteen SRIs with no follow-up documentation done by the Service Coordinator; 9 of those occurring in the first quarter of the fiscal year. There were three incidents that did not have numbers assigned to them, but were discovered by reading the notes section of MCIS. Most of these incidences occurred in the natural home setting and may be attributed to natural homes not keeping Service Coordinators in the loop or not being aware of the policies for notification of incidents.

It was a sure sign of improved oversight by the Health & Wellness unit involved that 100% of the UEIH involving people residing in their natural home had evidence of follow-up by the Health and Wellness Unit documented in MCIS.

A total of 53 UEIH involving psychiatric diagnoses were reviewed for FY13. The 53 UEIH occurred in a total of 34 people. Twenty-three (45%) SRI used the terms “aggression, aggressive, or escalation” in the description of incident section of the incident report form. One hundred percent of the 24 UEIH related to aggression where in people being supported with a

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<sup>29</sup> See, e.g., New Mexico Department of Health, *DDSD Aspiration Risk Screening Tool* (August 2009), available at <http://www.health.state.nm.us/ddsd/index.htm> (last visited Feb. 5, 2014).

Behavioral Support Plan (BSP). This is significant for two reasons; these are not construed as new episodes of aggression and there are documented approaches for the unlicensed assistive personnel to guide their actions. Unfortunately, the actions of staff were not adequate to avert the crisis in these instances.

Two Surgeon General reports<sup>30</sup> as well as the Centers for Disease Control and Prevention's Healthy People 2020<sup>31</sup> speak to the need for improved health care for individuals of all ages as well as those with developmental disabilities. We recommend that these documents be used to guide Evidence-based nursing practice (EBP) in people diagnosed with an intellectual or other developmental disability in the District of Columbia.

Research has consistently documented that people with intellectual and developmental disabilities experience poorer health outcomes than the general.<sup>32</sup> Current literature suggests that the number of older adults with intellectual and developmental disabilities (IDD) has increased rapidly in the United States as part of the general "graying" of the country.<sup>33</sup> This has presented challenges in maintaining the quality of life and health for these individuals in later years. Issues including diagnostic overshadowing (the tendency to overlook symptoms of mental or physical illness as causes for decline), lack of knowledge about aging in adults with IDD, and health care disparities must be acknowledged and addressed in order to improve and maintain healthy lives.

The HCM also reviewed the deaths of 12 people in this sample as depicted in the following table:

#	Gender	Age at death	Setting	FY 2013 Prior hospitalizations	Days between hospital and death	Admission Diagnosis
1	Male	40	Natural Home	1	64	Sepsis, bronchospasm r/t stage IV decubitus
2	Female	49	ICF/IDD	1	2	GI Bleed, Possible bowel obstruction, Sepsis UTI
3	Female	38	Natural Home	2	25	Lethargy, fever, poor po intake, altered mental status d/t high valproic acid level – no cause of

<sup>30</sup> See U.S. DEPT. OF HEALTH & HUMAN SERVICES, *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation, Report of the Surgeon General's Conference on Health Disparities and Mental Retardation* (2002); U.S. DEPT. OF HEALTH & HUMAN SERVICES, *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* (2005), available at <http://www.surgeongeneral.gov/library/calls/disabilities/calltoaction.pdf> (last visited Jan. 30, 2014).

<sup>31</sup> U.S. DEPT. OF HEALTH & HUMAN SERVICES, *Healthy People 2020*, available at <http://www.healthypeople.gov/2020/default.aspx> (last visited Jan. 30, 2014).

<sup>32</sup> G.L. Krahn & C.E. Drum, *Translating Policy Principles into Practice to Improve Health Care Access for Adults with Intellectual Disabilities: A Research Review of the Past Decade*, 13 *Mental Retardation & Developmental Disabilities Research Reviews* 2, at 160 (2007).

<sup>33</sup> See Wan He, Mark N. Muenchrath, and Paul Kowal, *Shades of Gray: A Cross-Country Study of Health & Well-Being of Older Populations in SAFE Countries, 2007-2010* (May 2012), available at <http://www.census.gov/prod/2012pubs/p95-12-01.pdf> (last visited Feb. 5, 2014).

#	Gender	Age at death	Setting	FY 2013 Prior hospitalizations	Days between hospital and death	Admission Diagnosis
						death noted
4	Male	51	Natural Home	1	67	Esophageal varices which was a result of due to his liver sclerosis
5	Female	41	ICF/IDD	2	17	Shock d/t hypotension Pneumonia Unspecified
6	Female	23	Natural Home	1	12	Aicardi syndrome/Hospice care
7	Female	85	Waiver-Residential Habilitation	2	12	COPD, Pneumonia-Unspecified Dysphagia ?aspiration DX large Hiatal Hernia
8	Male	74	ICF/IDD	2 discharged 5/2/13 and readmitted 5/14/13	4	Severe Anemia, Malnutrition, Stage IV decubitus – sacrum ?Multiple myeloma Cardiac arrest
9	Male	31	Waiver-Supported Living	1	2	LTAC from hospital Pneumonia – Unspecified, tachycardia, and “blood infection-MRSA”
10	Male	57	Waiver-Supported Living	1 Interesting aside: he eloped three times prior to these admissions and went to the hospital each time-? r/t pain from stones	2	Prior ER visit-dx with inguinal hernia  obstructive jaundice, sepsis and severe hypotension, cholangitis/cholecystitis
11	Male	59	ICF/IDD	3 4 in FY12	10	right frontal lobe brain hemorrhage unspecified cause
12	Female	29	Natural Home	6	6 months	Pneumonia several times; very poor documentation – no note regarding death found

As depicted above, ages at death ranged from 23 to 85 years old with the mean age of 48 years, below the national levels. Six (or 0.46%) of deaths occurred in people residing in Natural Home settings and 7 (or 0.54%) occurred in residential settings. The data depicted in this table is non-scientific and the assumptions made are based on statements taken from reports – the final critique will be completed through the Mortality Review process, which is a component of DDS’ Quality Assurance Plan. Six of the 13 deaths were related to pneumonia with no

documented specification of the type of pneumonia (community acquired as opposed to aspiration); therefore it is impossible to make assumptions or recommendations. The raw data is certainly indicative of the types of issues seen in this population nationally and suggestive of areas where improvements can be made regarding education, competency checks, and follow-up.

Diagnostic overshadowing is an emerging trend in health care pertaining to this subspecialty. The tendency for health care professionals to ignore physical or mental illness symptoms in this subpopulation and then blaming the resulting decline on the primary diagnosis or the chronological age adds challenges for maintaining quality of health and life in later years. Front line registered nurses must be educated on aging in this population, must demonstrate exceptional assessment skills, be proficient in training unlicensed assistive personnel and be monitored for competency. Only then will people with I/DD in the District of Columbia be assured of consistently acceptable health care and oversight.

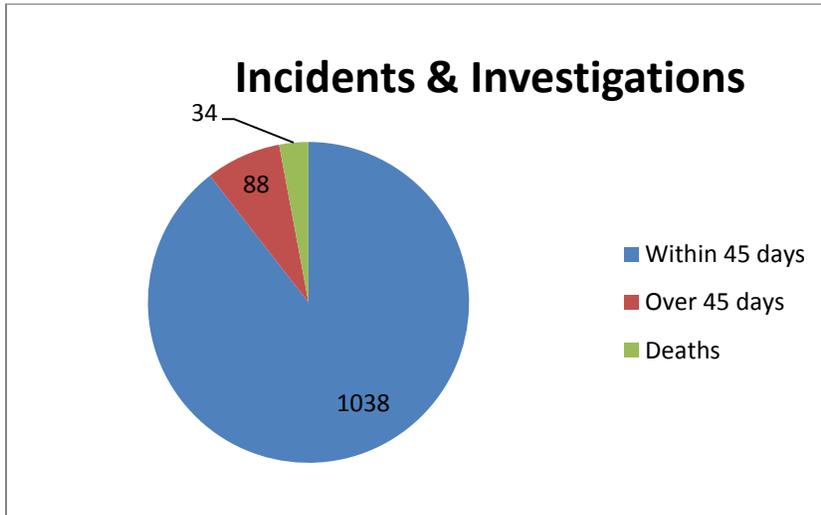
### Serious Reportable Incidents & Investigations

Since 2010 steady improvement has been made within the Incident Management & Enforcement Unit of DDS. While the number of outstanding investigations began to shrink in 2011, improving quality was harder to achieve. This year there was an increase in quality as measured but the “Checklist for Quality”, the tool used to gauge quality of investigations by both Quality Trust and DDS for several years now. Of the 308 investigations reviewed for non-*Evans* class members, 166 involved Abuse, Neglect or Serious Physical Injury. Per the DDS policy in place until June 1, 2013, IMEU investigators assumed the lead role in these investigations.<sup>34</sup> For those incident types we found:

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<sup>34</sup> See Wan He, Mark N. Muenchrath, and Paul Kowel, *Shades of Gray: A Cross Country Study of Health & Well-Being of Older Populations in SAFE Countries, 2007-2010* (May 2012), available at <http://www.census.gov/prod/2012pubs/p95-12-01.pdf> (last visited Feb. 5, 2014).

\*The first bullet is a total number including both class non class members. The rest of the bullets involve non class members only.



- 92% of investigations were completed on time (1038 of 1126)
- 87% (145 of 166) included evidence of a visit to the scene
- 24% (24 of 166) of those visits were made within the first 24 hours (the June 1, 2013 resulted in a change in the policy which will increase this number significantly)
- 82% (131 of 166) included an interview with the alleged victim
- 62% (102 of 166) included an interview with the alleged perpetrator (this number is affected by the fact that in several instances the alleged perpetrator was removed by the provider after they admitted responsibility, so no interview by IMEU was necessary)
- 90% (147 of 166) of the investigations contained evidence that past incidents had been reviewed for tracking and trending purposes
- 88% included analysis and questions necessary to adequately conclude the investigation

## Post Compliance Monitoring in the *Evans* Case

The 2010 Update of the 2001 Plan for Compliance was approved by the Judge in the *Evans* case in August of 2010. The plan contained a framework through which the remaining issues in the case could be completed. In August of 2010 there were nine goal areas containing 70 individual criteria requiring completion. In his September 28, 2012 report, the Special Master found the District in compliance for three of the nine goal areas (A. 4, staff training, C. Personal Possessions, and F. Adequate Budget). At the October 28, 2012 Hearing the Judge issued her ruling in favor of the District.

In March and again in April of 2013, DDS issued new policies involving provider requirements for training.<sup>35</sup> Overall these policies reflect improved standards such as requiring all staff; including clinical staff to receive training. They also increase the number of subject areas those working directly with people receiving services must receive. Finally, they require on-going training (level IV) training, not previously required in policy. We decided to wait a period of time (three months) before beginning our monitoring so that providers would have time to modify their internal procedures for meeting the new requirements. We also realized that doing so would give us little time to complete substantial monitoring before the end of the fiscal year. We decided therefore to use that time to perfect our own understanding of the new requirements, develop appropriate questions and test these on a small group of people.

Using a list of approximately 160 class members not previously reviewed by the Court Monitor's office we randomly selected a group of 34 people, or 22% (34 of 160). When we began the work in July of 2013 there was a wide range of understanding and comfort with the new requirements among the providers we visited. As we reached the end of the fiscal year, the required information was more readily available. We also noticed an improvement in the clarity of providers as to the new requirements and their ability to demonstrate their success documenting their staff had the required training. Having seen so few people with the time available to us, we have decided not to include the data gathered so far on this goal area.

In an effort to gather statistically significant data on staff training rather than smaller less illuminating sample, we have included the staff training questions into our monitoring tool. Our aim is to complete a statistically significant random sample of all of the 2190 people in the DD system. The data we are gathering this year, which will be reported on in our next report will provide more reliable data regarding staff training system wide.

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<sup>35</sup> See DDS, Direct Support Professional Training Structure Requirements (March 1, 2013), *available at* [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/Administrative%20DDS/DSP%20Training%20Structure%20Requirements%203-1-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/Administrative%20DDS/DSP%20Training%20Structure%20Requirements%203-1-2013.pdf) (last visited Jan. 30, 2014); DDS, Enhanced Curriculum Objectives and Competencies (March 1, 2013), *available at* [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/Administrative%20DDS/Enhanced%20Curriculum%20Objectives%20and%20Competencie%203-1-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/Administrative%20DDS/Enhanced%20Curriculum%20Objectives%20and%20Competencie%203-1-2013.pdf) (last visited Jan. 30, 2014); DDS, Direct Support Training Policy (April 14, 2013), *available at* [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/DSP%20Training%20Policy%204-24-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/DSP%20Training%20Policy%204-24-2013.pdf) (last visited Jan. 30, 2014); DDS, Direct Support Professional Training Procedures (eff. April 30, 2013), *available at* [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/DSP%20Training%20Procedure%204-24-2013.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/DSP%20Training%20Procedure%204-24-2013.pdf) (last visited Jan. 30, 2014)

While we conducted the monitoring regarding staff training, we also included questions regarding protection of personal funds (taken directly from the Joint Monitoring questionnaire). Again, the results were encouraging, but given the small number of people monitored we have chosen not to include that data in this report, but can say that the rate of compliance note was just fewer than 100%. As with staff training though, we have also added the questions regarding protection of person funds to our monitoring tool this year. We will include the data gathered throughout the current year monitoring on both these issues in our report next year.

The final goal area approved in October of 2012 involved the adequate budget. There are two specific criteria included, the first of which contains three parts. Goal one requires that DDS will maintain a ratio of one service coordinator for every 30 consumers; Part two requires that DDS retain sufficient staff for investigations of incidents to meet a ratio of 10 investigations per month per investigator; And part three calls for DDS to retain sufficient staff capacity to conduct eight provider certification reviews per month.”

Goal two requires that DDS will produce a report every six months in which unmet needs will be aggregated and the cause for those unmet needs will be analyzed. The goal requires that if lack of funding is determined to be the cause for any unmet needs, that the funding strategies will be implemented within the next budget cycle. Finally goal two requires the District government to maintain sufficient budget to allow the transition of class members to the Medicaid waiver as recommended in the ISP process.

Taking these issues in reverse, according to the Department of Healthcare Financing the FY 2013 budget (approved in April of 2013) contained a total of \$235,682,667 million dollars of Medicaid spending on direct services. A breakout of that spending shows \$78,789,215 ICF/IDD, and \$156,893,452 waiver. The District’s share of this spending is 30%, or approximately \$70.7 million local dollars. As of June of 2013, the estimated increase in FY 2014 would call for total spending of \$96,920,709 in the ICF program, and \$180,317,491 in the waiver program for a total of \$277,238,200, an increase of \$41,555,533 or 17.6%. As of June of 2013, spending increased in both programs for FY 2014. An increase to \$96,920,709 in the ICF program, and \$180,317,491 in the waiver program for a total of \$277,238,200 was approved, an increase of \$41,555,533 or 17.6%. According to DDS there are currently 1574 people receiving services on the waiver for an average cost of \$114,560.00. There are 346 people living in ICFs/IDD, so the average cost per person for the ICF/IDD program is \$280,117.00.<sup>36</sup> The consistent increase in DD services has been on-going for several years, and FY 2014 is no exception.

At the same time, in September of 2013 DDS instituted its first waiting list policy for HCBS waiver services.<sup>37</sup> According to DDS, no one is currently on the list, nor do they anticipate anyone will be added during the current fiscal year.

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<sup>36</sup> Information provided to us by the DDS Quality Management Division

<sup>37</sup> See DDS, Waiting List for the HCBS IDD Waiver Policy (eff. August 15, 2013), *available at* [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/Waiting%20List%20for%20the%20HCBS%20IDD%20Waiver%20Policy.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/Waiting%20List%20for%20the%20HCBS%20IDD%20Waiver%20Policy.pdf) (last visited Jan. 30, 2014); DDS, Waiting List for the HCBS IDD Waiver Procedure (eff. August 15, 2013), *available at* [http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS\\_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/Waiting%20List%20for%20the%20HCBS%20IDD%20Waiver%20Procedure.pdf](http://dds.dc.gov/DC/DDS/DDS%20Publication%20Files/DDS_files/Policy/Program%20Policie-General%20Administrative%20Policies/Program%20Policies-DDS%20DDA/2012/V%20Provider%20Network/Waiting%20List%20for%20the%20HCBS%20IDD%20Waiver%20Procedure.pdf) (last visited Jan. 30, 2014).

The current HCBS waiver was approved by CMS in November of 2012. The current waiver does not include many new services (Individualized Day Supports, Supported Living with transportation, and Skilled Nursing Services being the exception). It does set more rigorous standards and sets out higher expectations of providers-especially in the area of Quality Assurance. Much has been made of the fact that the rules (regulations) for each of the 26 services included in the waiver have not been published as finally approved some 15 months after the waiver was approved by the Federal government. The Director of DDS assures stakeholders that all services are now and have always been available since November of 2012. While that said, and given that there were so few changes or additions to the previous waiver, it is concerning that the process employed by the District of Columbia apparently results in a back and forth process that stretches out more than a year after approval of the waiver itself.

According to the most recent unmet needs report issued by DDS which covers the timeframe January 2013 to June 2013, there were 153 unmet needs recorded for 80 Evans class members. The report identifies people residing in ICFs/IDD as the group most affected by having unmet needs (77 of 153 unmet needs). It states further that a good number of the unmet needs for that group were discovered during monitoring completed by the Court Monitor during the month of March 2013. The second largest number of identified unmet needs highlighted (54 of 153) live in Supported Living; a waiver service. The report indicates that Service Coordinators discovered the highest number of unmet needs (54.4%) through their Monitoring Tools which are completed during their required eight visits per year.

Of the 153 unmet needs identified, 92% (141 of 153) were closed within the six months covered during the report. The health Domain accounted for the highest number of unmet needs (82 of 153), with the second largest number coming from problems with adaptive equipment. We know from the on-going reporting of the Independent Compliance Administrator in the *Evans* case that timely acquisition and maintenance of adaptive equipment remains a challenge and concern. DDS has contracted with a provider to resolve issues when needed adaptive equipment has taken longer than 60 days to acquire. Since the report only addresses need identified for class members, it is unclear if a more systemic report is also produced involving both class and non-class members.

According to DDS, all Service Coordinators continue to maintain ratios of 1:30 and the number of Incident Management and Enforcement Unit investigation closures From December 1, 2012 through November 30, 2013, was 384 *Evans* SRI investigations closed (average of 32 closures per month).

## Final Conclusions

Most of the people receiving services in the District of Columbia are young and relatively healthy. Their expectations center on working, and experiencing an integrated and varied social life with family and friends. There are currently 530 *Evans* class members who are over the age of 50 years old, and for whom life “in the community” began in or around 1989. On the face of it these two groups are different, but in so many ways they are alike. All want and need opportunities outside of sheltered workshops and congregate living homes. To benefit from those kinds of experiences they some first need the benefit of coordinated and, at least adequate medical and behavioral health services. Having raised expectations amongst its many stakeholders, it is now the responsibility of DDS to ensure the delivery on a consistent basis of high quality services and supports to the approximately 2190 people in the DD system in the District of Columbia.