

Fiscal Year 2017 Second Quarter Results

May 2017

INTRODUCTION

The 2001 Plan for Compliance and Conclusion in the *Evans* case included amongst its many outcomes the creation and funding of Quality Trust. Quality Trust was intended to be a permanent monitor and mechanism for safeguarding all people with intellectual and other developmental disabilities served by the District and to continue its operations after the termination of the case. Now that the case has been concluded, Quality Trust is fulfilling that mandate to monitor and advocate for everyone receiving services through the auspices of the District of Columbia, Department of Disabilities Services.

This is the second quarter report of results from our monitoring during the period January 1st to March 31st 2017.

Overall the statistical results of our random monitoring of 51 people include several positive findings, while areas needing improvement are also clearly apparent. We have encountered several situations at the individual level which cause concern about the quality of provider services and DDS Service Coordinator monitoring and advocacy for specific people.

It is not unusual for both findings to occur simultaneously, and will no doubt be the norm going forward. Of course, providing the exact support at the appropriate level for each person is the goal. In a multi-level community based system however, mistakes of omission and commission occur. Thinking of services from the inside out, those closest to the person, who we call Direct Support Professionals (DSP's) MUST possess the skills they need, the judgment to react to unexpected changes, and direction of executive level staff at their provider agencies to ensure they are prepared. The same can be said for DDS, Service Coordinators in whom much responsibility for front line advocacy and monitoring are vested. Executive level staff at residential and day program providers and Developmental Disabilities Administration staff must ensure through rigorous Quality Improvement an Assurance (QI/QA) strategies that policy makers know, in real time what is working and what is not. When repeated failures that pose risk to people receiving supports and services are identified, interventions must be readily available to address their consequences.

Methodology

The data contained in this report is broken down into the following sections: results from random sampling monitoring, results from Triaging of Serious Reportable Incidents, updates to our involvement with people through advocacy.

To provide the most useful information to members of the City Council, families of people receiving services, providers and other advocates for people with developmental disabilities in the District of Columbia we set as our goal the completion of a statistically significant random sample of all people currently receiving services and supports; 2293. To attain the required level of certainty our sample will include 329 people. To further enhance the accuracy of our results we analyzed some basic demographic characteristics of the 2293 people; looking at sex, enrollment in the waiver, whether the person resides at home or in congregate living arrangements and whether the person resided at Forest Haven or not. Now that the *Evans* case has been settled we have decided not to present class status in our public reports, however we will continue to note that information in our database. The characteristics of our sample match the larger group of people receiving services within two percentage points; well within the margin of error.

Results from Quarter One Random Sample Monitoring

The following highlights are drawn from our review of 51 people during the period January 1, 2017 to March 31, 2017.

DEMOGRAPHICS

- 76% (39) people were enrolled on the Home & Community Based Services Medicaid waiver

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- 24% (12) were not on the waiver
- 18% (9) live in Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/IDD)
- 62% (24/39) live in Supported Living, the least restrictive residential available in the District
- 10% (4/39) live in Residential Habilitation, a waived group home model of congregated living
- 5% (2) live in Host Homes; a version of Adult Foster Care
- 31% (12/39) live in the family or Natural Home
- Out of the 12 people not on the waiver, 9 were in ICFs, 2 people live in a family home and are employed and 1 person lives in the family home and goes to college
- **These positive results reflecting extensive use of least restrictive models is consistent with previous samples**
- 29% (15) former residents of Forest Haven
- 71% (36) people who never resided at Forest Haven
- 33% (17) had no formal day program supports or services
- The largest age group was 51-60 with 18 people (35%), followed by 21-30 with 13 people (25%)
- 76% (39) were male
- 24% (12) were female
- **These gender results are comparable with previous samples**

CHARACTERISTICS

- 75% (38) walk independently
- 44% (28) use language to communicate
- 84% (43) have relationships with people other than paid staff
- 73% (37) people use at least one piece of adaptive equipment

SERVICE PLANNING

- 96% (49 of 51) people had a current Individual Service Plan
- 89% (39 of 45) people had day program goals which favored community based activities
- 100% of ISP's requiring updates, or other modifications had those changes

STAFF TRAINING

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- 72% of people's residential staff had all required trainings
- 80% of people's residential staff were engaged in meaningful activity during our visits
- 89% of people's residential staff could demonstrate the knowledge and skills necessary to carry out the person's goals and outcomes
- 88% of people's day program staff had all required trainings
- 90% of people's day program staff were engaged in meaningful activity during visits
- 94% of people's day program staff could demonstrate knowledge and skill necessary to carry out the person's goals and outcomes

NURSING AND HEALTHCARE SUPPORTS & SERVICES

- **From highest to lowest in occurrence, the following represent the most common indicators observed**
- *18% (17/44) had bowel elimination problems
- *18% (17/44) had hypertension
- *13% (12/44) had a seizure diagnosis
- *13% (12/44) were overweight
- *9% (8/44) had choking precautions in place
- *6% (6/44) had diabetes
- * These percentages do not equal 100% because one person can, and often do have more than one diagnosis

USE OF PSYCHOTROPIC MEDICATIONS

- 45% (21/47) are taking no psychotropic medications
- 23% (11/47) are taking one psychotropic medication
- 13% (6/47) are taking two psychotropic medications
- 10% (5/47) are taking three psychotropic medications
- 2% (1/47) are taking four psychotropic medications
- 2% (1/47) are taking five psychotropic medications
- 2% (1/47) are taking over five psychotropic medications
- **The use of four or more psychotropic medications (poly pharmacy) is of great concern**

USE OF NEUROLEPTIC MEDICATIONS

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- 69% (33/48) are taking no seizure medications
- 19% (9/48) are taking 1 seizure medication
- 4% (2/48) are taking 2 seizure medications
- 10% (5/48) are taking seizure medications for behavior management

NURSING SUPPORTS & SERVICES

- 92% (44/48) people had a current physical
- 63% (30/48) people had recommendations from the PCP implemented
- 88% (42/48) people had dental recommendations implemented
- 77% (27/35) people had a Health Care Management Plan (HCMP) that referenced all their health needs
- 78% (28/36) people had a Direct Support Professional (DSP) that could describe their responsibilities
- 84% (32/38) people's staff were trained on HCMP updates
- 72% (24/33) people's staff had were knowledgeable of intended effects and side effects

DDS SERVICE COORDINATORS MONITORING AND ADVOCACY

- 69% (35/51) DDS Service Coordinators ensured the delivery of services outlined in the ISP
- 63% (32/51) identified issues in monitoring tools
- 69% (35/51) completed monitoring tools as required

Conclusion

The demographic data continue trends which have recurred through many of our previous samples. Where findings have been positive in previous reports, they continue to be in the second quarter of 2017. Where the findings show a need for improvement, that trend has been maintained as well. This consistency (both positive and negative findings) strengthens previous conclusions.

We are encouraged that so many people have community based day program goals, but many times those activities we encounter still lack meaningful integration into the social makeup of the community. While the percentage of documented of current staff training was modest (72%), the active involvement numbers are encouraging. The findings around use of multiple psychotropic medications is disturbing, and is a matter which should be explored in depth not only by the RCRC, but also the HRC. Our findings that health care plans and training o DSP's on these plans being in the mid 70 percent range is in keeping with several of our past reports. This is an area where continued improvement is essential. As we said in the beginning of this report, without well trained and motivated staff, little good can occur for people over the long run. Our poor findings related to DDS Service Coordination follow up are also not new, and their improvement should be a priority for senior leadership at DDA and DDS.

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Incidents and Their Investigations

During the second quarter of FY 2017 Quality Trust received 335 Serious Reports Incidents, SRI's, an increase of 90 incidents from the first quarter. The following is a breakdown of those incidents by type.

Incidents Q2	Total Incidents	Percentage of total
Unplanned Emergency Inpatient Hospitalizations	122	(36%)
Neglect	96	(29%)
Abuse	33	(10%)
Serious Physical Injury	25	(7%)
Exploitation	22	(7%)
Missing Person	17	(5%)
Death	11	(3%)
Serious Medication Error	9	(3%)
Other	2	(<1%)
Total	337	(100%)

Breakdown of incidents and percent change Q1 V. Q 2

Incidents Q2	Percentage of total	Incidents Q1	Percentage of total	Change from Q 1	Percentage change from Q 1
Unplanned Emergency Inpatient Hospitalizations (UEIH) = 122	(36%)	91	(38%)	+31	+34%
Neglect = 96	(29%)	46	(19%)	+50	+109%
Abuse = 33	(10%)	27	(11%)	+5	++22%
Serious Physical Injury = 25	(7%)	30	(12%)	-5	-17%
Exploitation = 22	(7%)	22	(9%)	None	None
Missing Person= 17	(5%)	8	(3%)	+9	+112%
Death = 11	(3%)	15	(6%)	-4	-26%
Serious Medication Error=9	(3%)	3	(1%)	+6	+200%
Other= 2	(<1%)		(<1%)	N/A	N/A
Total =337	(100%)	224	(100%)		

Incidents Q2	Total	Number of closed investigations	Number resolved- no abuse or neglect found	Number substantiated for neglect	Number Unresolved-upgraded to neglect or abuse
Unplanned Emergency Inpatient Hospitalizations	122	92 (75%)	77 (78%)	3 (3%)	2 (2%)
Serious Physical Injury	25	20 (80%)	16 (80%)	3 (15%)	N/A
Exploitation	22	12 (55%)	5 (42%)	6 (50%)	1 (8%)

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Serious Medication Error	5	3	2	1	
	Total	Number of Closed Investigations	Number Unsubstantiated	Number Substantiated	Number Inconclusive
Neglect	96	72 (75%)	15 (21%)	47 (65%)	2 (3%)
Abuse	33	20 (61%)	8 (40%)	5 (25%)	1 (5%)
Death	11	N/A	N/A	N/A	N/A
Total	337	219 (65%)	168 (77%)	65 (30%)	6 (3%)

Understanding Serious Reportable Incident data:

The Developmental Disabilities Administration (DDA) of the Department of Disability Services (DDS) categorizes incidents relative to their seriousness and the risk they pose to people receiving service and supports. Significant incidents, those that cause potential for serious harm and/or loss of personal possessions through exploitation, are defined in policy as Serious Reportable Incidents. Those incidents characterized as presenting less harm are defined as Reportable Incidents. The list above represents the eight most numerous incident categories during the second quarter of FY 2017.

Unplanned Emergency Inpatient Hospitalizations (UEIH), were once again the highest category of incident in quarter two. The 122 UEIH's, and increase of 31 were the single biggest category of Serious Reportable Incidents. We have commented on the continued disproportionate occurrence of this incident type in many of our previous reports, so we won't rehash that issue here. We are currently working with DDS staff in the Quality Improvement Committee to look at potential underlying issues which may help to explain why people go to the hospital in an unplanned way. The most striking result in incident data in quarter two, was the **100+% increase** in neglect. We have no explanation for this result, and have requested that DDS provide their analysis of the cause. Of the 96 neglect incidents in Q2, seventy-two (72) were closed. Of the 72 closed investigations for neglect 47 (65%) were substantiated. Over the past several quarters neglect is substantiated in most investigations. The third most numerous category was abuse, at 33 incidents, 20 (41%) had closed investigations. Of those, 8 were substantiated and five were unsubstantiated. No single provider accounted for more than four of the substantiated neglect or abuse incidents.

As you can see from the data above, except for Neglect, where 65% of investigations were substantiated, substantiation is low in all the other categories of Serious Reportable Incidents.

We continue to be concerned that the number of deaths remained relatively consistent. There were 15 deaths in the first quarter, and 11 this quarter. There were 35 deaths during FY 2016. At our current pace, we could expect close to 50 deaths this year. That would be a substantial and significant increase. Because of these findings we have altered our monitoring process to include a visit to the home or day program by our team as soon as we receive notification. We will not complete that type of visit to a hospital or LTAC facility, but we will request information from them.

Serious Reportable Triage

Total number of incidents triaged: 359

UEIH:132

- Of the Unplanned Emergency Inpatient Hospitalizations (UEIH) Triaged, 27 people (20%), lived in their natural home, 63 (48%) lived in Supported Living, 34 (26%) in ICF/IDD and 6 (6%) in Residential Habilitation
- 72 of the 132 (55%) people had not experienced another UEIH incident in the past 6 months

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- Out of 132 incidents, 19 (14%) were psychiatric in nature
 - 9 out of those 19 (47%) went to CPEP for triage and 10 (53%) involved the police
 - 17 out of the 19 people (89%) were prescribed Psychotropic medications, per MCIS, and 15 out of 19 (79%) had a current Behavior Support Plan (BSP)
 - 3 people had a BSP that was not current and 1 did not have evidence of a BSP.
 - People were admitted to the hospital with some common concerns/diagnosis. Breathing problems was listed on the incident reports as the most common concern, after which was pneumonia, seizures and vomiting
 - There were 16 incidents of people who were brought into the hospital because they were weak and unresponsive.

Number of people who had evidence of being admitted for a certain diagnosis/problem	Diagnosis/Concern
16	Weak, unresponsive
14	Breathing Problems
12	Pneumonia
9	Seizures
9	Vomiting
5	G tube
3	Urinary Tract Infection
2	Constipation
1	Stroke
1	Sepsis

All other SRIs: 227

- 30% (68/227) had prior serious reportable incidents within 60 days
- 16% (36/227) were abuse incidents
 - 11% (4/36) of the abuse incidents resulted in calling the police
 - 3% (1/36) of the abuse incidents resulted in calling APS
 - 6% (2/36) of the abuse incidents involved someone going to the hospital
- 47% (106/227) were neglect incidents
 - 39% (41/106) of the neglect incidents were medical neglect
 - 86% (91/106) of the neglect incidents were due to provider staff
 - 7% (7/106) of the neglect incidents were from family
 - 7% (7/106) of the neglect incidents were due to transportation providers
- 10% (22/227) were exploitation incidents
- 15% (33/227) were serious physical injuries
 - 67 (22/33) of the serious physical injuries were caused by accidents
 - 33% (11/33) of injuries were caused by a behavioral episode. 4 people had injuries from SIB, 3 from accidents during a behavioral episode and 2 people injured by strangers while having a behavioral incident.
 - 45% (5/11) of the people involved in a behavioral incident causing injury had a current BSP.
 - 45% (5/11) of the people involved in a behavioral incident causing injury had no BSP
 - 9% (1/11) person involved in a behavioral episode causing injury had an expired BSP

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Advocacy

People in active advocacy: 14
 People referred to legal: 0
 Advocacy requests referred Family Services: 0
 Outcomes Met or Closed: 10
 New Referrals: 9

Number of Outcomes Met	Outcome
2	Residential move or supports
4	Closed by the person/family
1	Financial support/change in SSI payee
1	Died
2	Unresponsive in process
1	Enrolled in college
1	Adaptive equipment fixed
1	Day program scheduling

Referral Source	Number of referrals
The person needing support	0
Family	3
Provider	0
QT Attorneys	0
DDS SC	3
QT monitoring	2
Outside agency	1 (hospital SW)

LTAC Follow Up

Number of LTAC follow Up Visits: 7 (9 received, but 2 were received on the last day of the month, and visits will be made next quarter.)

- We received notification from DDS of 9 people going into LTAC. That is 100% notification. We reviewed 7/9 of those people, as the last two notifications arrived on the last day of the quarter.
- Six people went to LTAC and all placements were deemed necessary after a visit from the QT Monitor.
- Two people were unable to return to their previous home; one was referred to another more accessible home within the same provider and one was referred from supported living to an ICF level of care.
- One person continues to receive advocacy from the Quality Trust. That person had a major decline in health and will be leaving the provider he has lived with for over 30 years due to an ICF level of care.

Reason for LTAC (note that people have multiple reasons)	Number of people

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Wound care	2
PT/OT/Speech	5
Antibiotics	2
Skilled nursing	1

SRI Follow Up

Total SRI follow up: 20

- There were 20 follow up visits made through the triage process of all serious reportable incidents. At the time of the visit all 20 people were in their home and deemed safe by QT staff.
- 11 out of the 12 people who had an UEIH had recommendations made at the time of D/C. Ten out of those eleven were completed. One recommendation to obtain a nutritionist had not been followed up as recommended.
- When returning to their day programs after a hospitalization, only 2 out of the 8 people who had a day program had not returned at the time of the visit.

Incident Type	Number
UEIH	12
Neglect	5
Abuse	2
Serious Physical Injury	1

RCRC Review:

Quality Trust's reviews and analyzes the data from the meeting minutes of the Restrictive Control Review Committee ("RCRC"), which reviews behavioral support plans to ensure restrictive controls within them are appropriately justified. These minutes are provided by DDS monthly.

Based on that review, during the second quarter of Fiscal Year 2017:

- The RCRC reviewed a total of 206 Behavioral Support Plans ("BSPs") for 190 people.
 - Most reviews were identified as non-emergency reviews of new BSPs (152;74%) and updated BSPs (27, 13%)
 - 1 BSP was identified as being reviewed on an emergency basis.
 - 26 BSPs (13%) were not reviewed on an emergency basis and were not specifically identified in the minutes as new or updated.
- Of the BSPs reviewed, 179 (87%) were approved, 2 (1%) were approved for 90 days only, and 1 (less than 1%) was approved for 30 days only.
 - 61 (30%) of these BSPs were approved even though the RCRC minutes included substantive comments requiring the revision of the BSP and/or raising issues that called into question whether the BSP met the 8 required criteria listed in DDS' RCRC Procedure.¹

¹ See DDS Procedure No. 2013-DDA-PR014, Section 3(D)(3), available at <https://dds.dc.gov/node/739062>. These 8 criteria include: (1) Does the BSP include targeted behavior that is consistent with the person's diagnosis? (2) Does the BSP include relevant data collection? (3) Does the BSP include demonstrated review of the data by the psychologist? (4) Does the BSP include procedures to address behavioral issues consistent with DDA policies? (5) Does the BSP include a functional analysis? (6) Are there proactive, positive strategies identified in the BSP? (7) Is there a

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- Illustrative examples follow:
 - Example 1: RCRC approved a BSP and found all 8 required criteria were unequivocally met, yet its minutes reflect that the psychotropic medications referenced in the BSP were “being given for a diagnosis [the person] does not have.” Such a finding raises questions as to whether the BSP met criteria #1, #4, and #7.
 - Example 2: RCRC approved a BSP and found all 8 required criteria were unequivocally met, yet its minutes reflect it required the BSP developer to develop a “plan for how data should be collected.” Such a finding raises questions as to whether the BSP met criterion #2.
- 5 (2%) of the BSPs were rejected.
- 19 (9%) of the BSPs were deferred.
 - 17 of these BSPs were deferred, rather than rejected, even though the RCRC answered “No” to one or more of the 8 criteria listed in DDS’ RCRC Procedure.
- The four most common restrictive controls reviewed were the use of psychotropic medications (within 199 or 97% of the BSPs), behavioral one-to-one aides (within 68 or 33% of the BSPs), “sharps restriction” (within 20 or 10% of the BSPs), and physical restraint (within 18 or 9% of the BSPs).
- The RCRC reviewed 9 requests for exemption from the requirement of having a BSP. All were approved.

As noted in our prior post-compliance reports, we had seen improvements made to the RCRC processes, as reflected in its minutes and in response to our prior recommendations. However, we are concerned that RCRC may be approving plans that it should be rejecting or deferring. For example, during the last quarter:

- 52 BSPs (25%) were approved until the end of the person’s current or next ISP year, even though the RCRC minutes also indicated that the BSPs should be revised and re-submitted for an updated review prior to that time.
- 26 BSPs (13%) were approved even though they included a restrictive control for which the RCRC requested further justification. Illustrative examples follow:
 - Example 1: RCRC approved a BSP and behavioral one-to-one aide (24 hours, 7 days a week) through the end of the ISP year, which was over 5 months away. It answered “Yes” to all the questions, including that there was a “rationale for restrictive interventions.” Yet it concluded that the “BSP needs to justify the use of the behavioral 1:1 during overnight hours,” and required a revised BSP to be uploaded into MCS within 15 days and subsequently reviewed by RCRC again. There were at least five additional similar scenarios involving overnight behavioral one-to-one aids this quarter.
 - Example 2: RCRC approved a BSP containing references to the use of CPI (a type of physical restraint) through the end of the next ISP year, almost two years away. Yet, RCRC also simultaneously expressed concern about the use of the CPI, because of the person’s medical conditions. RCRC required a clinical justification that the use of CPI is not medically contraindicated, and the submission of a revised BSP “as needed” within 30 days. There were at least three additional similar scenarios involving BSPs with CPI this quarter.

rational for using the restrictive interventions? (8) Are there benchmarks for reducing the restrictive interviews including a titration plan for medications (or statement of lowest effective dose based on prior attempts to reduce)? Under Section 3(D)(4)(a) of this Procedure, to approve a BSP, the Committee must find that a BSP meets all of these 8 criteria and “meets professional standards.”

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- 4 BSPs (2%) were approved even though they included a restrictive control that the RCRC expressly rejected or deferred a decision on. An illustrative example follows:
 - Example: RCRC approved a BSP through the end of the current ISP year, over 9 months away. However, it simultaneously rejected the use of a behavioral one-to-one aide (24 hours/7 days a week), which was a restrictive control described in the BSP, because it reportedly was not “effective.” The RCRC required a revised BSP to be uploaded into MCIS within 60 days, for subsequent review by the RCRC.

In such cases, it would appear to be more consistent with the intent of its procedures for RCRC to reject or defer the BSP to ensure that that the person’s team does not implement the unrevised BSP that contains elements the RCRC found problematic and/or unjustified.

HRAC Review:

Quality Trust analyzes the data from minutes of the Human Rights Advisory Committee (“HRAC”), which reviews human rights issues arising within the DDA system. For this quarter, DDS provided us with the minutes from HRAC meetings held on January 25, January 27 (an emergency meeting), February 22, and March 23, 2017.

Based on those minutes, during this quarter, the HRAC reviewed 32 human rights issues for 22 people.

- 9 issues were about Long Term Acute Care (“LTAC”) placements
- 9 issues were about nursing home placements
- 6 issues were about out-of-state placements
- 2 issues were about institutional placements
- 2 issues were about potential discharge from DDS and provider services
- 1 issue was about request for a one-bedroom apartment
- 1 issue was about a request for the use of protective mittens
- 1 issue was about parental access to a person’s programming
- 1 issue was about treatment refusal.

During this quarter HRAC also made systemic recommendations to DDS regarding policy changes needed to improve its review of out-of-state placements, so that it can ensure the HRAC has the information it needs to make the necessary nuanced and person-centered determinations about whether to approve the placement. While the minutes indicated that there were multiple HRAC discussions on this topic, the DDS policy and procedural changes were not finalized by the close of this quarter. We are concerned that HRAC is not being provided the information that it needs to review these placements in a timely way, as there were repeated instances this quarter where such reviews had to be deferred for months because of a lack of information being provided from DDS service coordination and the out-of-state provider. DDS should issue and implement the HRAC-requested policy change as expeditiously as possible to ensure that the human rights of DC citizens receiving DDA services and supports out-of-state are rigorously safeguarded.

CONCLUSION

During the second quarter of FY 2017 our monitoring results indicate that, on the whole improvements made by DDS over the past several years have been maintained. People have current ISP, those documents provide an accurate portrait of who they are, as well as what they want and need. The Incident Management & Enforcement Unit (IMEU) is completing their investigations which are thorough and timely. Many people we met are being provided with opportunities to spend at least part of their days outside of large “big box” day programs. Service Coordinators are documenting much of their work on behalf of people. At the same time, we continue to encounter significant failures at the level of the individual which give us serious concern.

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Mistakes of omission and commission occur. Direct Support Professionals (DSP's) and DDS Service Coordinators MUST possess the skills they need, the judgment to react to unexpected changes, and direction of executive level staff at their provider agencies to ensure they are prepared. Executive level staff at residential and day program providers and Developmental Disabilities Administration staff must ensure through rigorous Quality Improvement and Assurance (QI/QA) strategies that policy makers know, in real time what is working and what is not. When repeated failures that pose risk to people receiving supports and services are identified, interventions must be readily available to address their consequences.

The three bullets below (all below 70%) are concerning because they indicate that opportunities to intervene at the most immediate level are not fully realized. DDS Service Coordinators are charged with the responsibility of developing ISP's and ensuring that all required supports and services are being completed.

- 69% (35/51) DDS Service Coordinators ensured the delivery of services outlined in the ISP
- 63% (32/51) identified issues in monitoring tools
- 69% (35/51) completed monitoring tools as required

DDS has within its organizational structure the means to best intervene at the individual level. We will continue to monitor these performance indicators and others related to ensuring that the support that people need is provided in a timely and impactful manner.