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Third Quarter Monitoring Summary

April 1, 2019 – June 30, 2019

Introduction

This is the third quarterly monitoring and lay advocacy report for FY 2019. This report covering April 1, 2019 to June 30, 2019 describes Quality Trust's efforts to ensure the adequacy of services and supports for the approximately 2400 people in the District of Columbia's developmental disabilities system. As more and more people apply for services the adequacy of funding for expansion of services and supports in the District of Columbia into the future is now in question. In his testimony at the budget hearing in April 2019, regarding the adequacy of funding for FY 2020, the DDS Director indicated that there were no gaps anticipated. The During the third quarter however, The Developmental Disabilities Administration and the Department of Disabilities Services (DDA/DDS) informed stakeholders of significant changes to the way services will be offered going forward. These changes, which will be discussed in detail later in this report will reduce access to residential services to those people who meet a narrow set of circumstances and limit certain day program hours. Taken together with the previously announced changes requiring greater financial contributions by those receiving services to the cost of residential services, it appears the District of Columbia is approaching the point at which funding for DD services no longer adequate to meet demand. These observations are bolstered by feedback received from families of people both within and outside of formal IDD system in DC. Given these developments we fully expect requests for lay advocacy to increase significantly in the months and years ahead. At the same time access is becoming limited, we have concerns about the quality of the services currently available. Although not announced during the third quarter, DDS has decided not to continue the DDS Health Initiative implemented through a contract with the DC University Center on Excellence in Developmental Disabilities (UCEDD) at Georgetown. In our previous reports we have noted our significant concerns about the quality of healthcare services even with the Georgetown contract in place. We also note that there have been systemic improvements in nursing and clinical services as a result of the work of the Health Initiative. We have expressed concern about the lack of stakeholder engagement around the plan to transition these services to another provider and to staff internal to DDS. We await demonstrable evidence that DDS can design and carry through on sustainable nursing supports for the roughly 2400 people in the DD system in the District of Columbia. As we will demonstrate through data gathered related to our follow up on Serious Reportable Incidents (SRI's), and our work ensuring placements to Long Term Acute Care Facilities (LTACS), the provision of healthcare to the more than 2400 people comprising the DD system in the District has many weak points. This report also includes information about the quality of nursing services across congregate living models, and through our participation in the (MRC), Mortality Review

Committee, we review investigations of deaths completed by an independent entity; the Columbus Organization. Quality Trust has concerns about those investigations due to a lack of rigor in their findings and the few recommendations made for improvement regarding future service provision. We also receive the minutes from meetings of DDS's Restrictive Rights & Control Committee (RCRC) and Human Rights Committee (HRAC), which we analyze for trends. For both RCRC and HRAC, we are concerned that the committees are not always following DDS own policies and procedures. In the case of HRAC, we are concerned that, when it approves out-of-state and Long-Term Acute Care facility placements, it does not always record a finding that the person needs cannot be met in a less-restrictive environment. In the case of RCRC, we remain concerned that the committee is approving Behavioral Support Plans that should be deferred or rejected, pursuant to DDS policy and procedure.

Our monitoring project focused on Unplanned Inpatient Emergency Hepatizations (UEIH) is now in its third quarter of implementation. The focus of our analysis are the events surrounding unplanned hospitalizations, providers self-investigations, and DDS oversight of those investigations though the IMEU (Incident Management & Enforcement Unit). As with all our monitoring we construct a statistically significant random sample for its predictive value. Unplanned hospitalizations are the most numerous incident category regularly account for thirty seven percent (37%) of all incidents. Significantly, nearly all these incidents (97%) are closed with no fault found. More broadly, across all categories, the level of substantiation for all causes is 20% (21%, Q1 & 22% in Q2). In fact, as the charts in this report demonstrate, except for neglect (49%) and (exploitation (42%), in no incident category was the level of substantiation higher than twenty nine percent (29%). There is no expected level of substantiation (nor should there be), but the fact that after investigation, almost eight of ten incidents are not attributable to any failures of any kind on the part of those supporting people receiving services indicates an area for further exploration to verify that these are valid results.

In the case of level two incidents, the IMEU investigator reviews the provider investigation to ensure it meets standards set forth in policy. At the core of any investigation is answering the investigatory question. In these investigations that is: did an abusive or neglectful action cause the reported incident of abuse, neglect, a serious injury, exploitation an unplanned hospitalization. The final classifications for all investigations are: substantiated, unsubstantiated, resolved-no abuse or neglect found, inconclusive, administrative closure, and two sub classifications: substantiated for abuse and substantiated for neglect. These final classifications are often used when evidence in an investigation leads to findings for an alternative incident type. For example, if an investigation for serious physical injury leads to a substantiation for abuse, the incident is then reclassified as abuse.

Of specific concern to Quality Trust is the resolved-no abuse neglect found classification. As noted in the chart later in this report, in only two percent (2%) of incidents was the question answered in the affirmative. In fact, 84 of the 90 UEIH's closed this quarter (93%), were classified as resolved-no abuse or neglect found. This is a different classification than unsubstantiated. Had 93% of such incidents been unsubstantiated, a clear and unambiguous inference could be drawn that the provider's nursing or other supports did not cause the hospitalization. The classification of Resolved-No Abuse or Neglect Found leaves the question less clearly answered. If there was an issue found with the supports provided, the outcome should be substantiated. If there was no issue identified, there should be no substantiation. It is unclear why the category of Resolved-No Abuse or Neglect found is needed. This remains a concern to be addressed while DDS reviews and revises the IMEU policy and procedure. We appreciate that DDS has included us in the development of new policies and procedures for Serious Reportable Incidents, and we look forward to meaningful improvements as a result.

The following basic demographic data are presented to create context for the results contained in this report.

The five biggest residential settings continue to be:

- Natural Home: **954 (39%)**
- Supported Living: **941 (38%)**

- Intermediate Facility: **311 (13%)**
- Residential Habilitation: **119 (5%)**
- Host Home: **88 (3%)**
- All others: **49 (2%)**
- **TOTAL: 2413**

Nine people currently reside in out of state placements. The other fifteen living situations (including out of state placements) account for only forty-nine (49) people. There are 2462 people within the service delivery system.

Age Range	
Below 18	**0**
18 - 25	**334**
26 - 35	**586**
36 - 45	**389**
46 - 60	**586**
61 - 75	**449**
75 ABOVE	**56**
ALL	**2400**

Waiver	**1830**
ICF	**303**
Non ICF and Non Waiver	**270**

Advocacy

New referrals for advocacy: 10

This quarter saw systemic advocacy work with one specific provider. As part of the triage process a serious reportable incident follow up was assigned for a person who had several incidents including neglect and exploitation. One of these incidents implied that the provider was neglectful and abusive and was written by an employee who no longer worked there. When the Quality Trust Navigator went to visit the person there was environmental concerns were noted, and soon after the initial incident there were other incidents received for other people receiving support from the same provider. All the Navigators were assigned and everyone living with that provider was visited. Neglectful circumstances were noted in all of the homes, and included the following issues; bedbugs, roaches, ceilings with water damage, leaking bathtub, kitchen cabinets falling off the wall, lack of adequate food, boarded up doors within the home, dirty surroundings, broken furniture, bad odors in homes and an overall lack of support from staff in managing these issues. A meeting was held with the provider, DDS and the Quality Trust staff, and all the issues identified were discussed. At the meeting DDS required a plan of correction from the provider, to be submitted by the end of that week.

It should be noted that DDS had previously placed sanctions on this provider, however they did not produce meaningful improvement. It is important that DDS has mechanisms such as sanctions as a part of their overall continuous quality improvement strategy, but such actions must create demonstrable improvement with more urgency than happened in this situation.

The Quality Trust Navigators started monitoring the homes and continue to support people living with this provider. They routinely check on the progress being made on the homes of people living there. Because of QT advocacy all the above-mentioned concerns were resolved, and people now have safe and clean homes.

Sources of advocacy referrals

QT Internal referrals	Family
3	**7**

Requested outcomes from new referrals

DDA application support	1
New benefits or loss of benefits	1
Environmental concerns	1
Healthcare follow up	2
Residential change	1
DDS appeal	1
Concerns about exploitation	1
Requests for Spanish speaking support	1
Transition issues	1

Outcomes met / closed: 7

Number of Outcomes Met	Outcome
1	Residential move
1	Stayed in supported living rather than move to an ICF as suggested by the team
1	New guardian appointed
2	Medical recommendations completed
1	Family refused to participate
1	Person died

LTAC Follow UP

Number of LTAC follow Up Visits: 4

- We received notification from DDS of five (5) LTAC placements, but one person did not go to LTAC
- There were no concerns regarding appropriateness of setting at the time of placement
- One (1) person required additional follow-up from our nurses

Reason for LTAC (note that people have multiple reasons)	Number of people
Antibiotic Therapy	2
OT/ PT	1
General rehab	1

Serious Reportable Incident Follow Up

Total SRI follow-up: 12 assigned

Incident Type	Number
UEIH	6
Neglect	5
Exploitation	1

Follow-up Post Unplanned Emergency Inpatient Hospitalizations:

- 6/6 (100%) people had recommendations made at the time of discharge
- 2/6 (33%) had implemented their recommendations at the time of the visit
- 4/6 (67%) had recommended appointments scheduled at the time of the visit
- 6/6 (100%) people hospitalized reported feeling better
- 1/6 (17%) people needed continued advocacy for medical follow up.
- No new SRIs were generated after these visits

Non-medical follow up:

- All people were deemed to be safe after the visit
- No new SRIs were generated after these visits as well
- Responses to neglect included staff removal and staff training.

Deaths

- Twelve (12) deaths occurred this quarter
- One (1) death occurred in a nursing home
- The average age at time of death was 58
- The ages of the people who died were (31,35,54,75,54,80,54,63,49,74,67 & 63)

Serious Report Serious Reportable Incidents & Investigations Q 3

Total Incidents	Number closed	Number substantiated (substantiated & substantiated for neglect and/or abuse)	% substantiated	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)					% not substantiated				
288	276 (96%)	42 + 14 = 56	20%	114	30	19	27	220	41%	11 %	7 %	10 %	80 %

N =276 closed incidents

Breakdown of Serious Reportable Incidents Q3

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	104	37%	3% (3 of 104)	97% (101 of 104) • 98 resolved-No abuse or neglect found
Neglect	51	18%	49% (25 of 51)	51% (26 of 51)
Serious Physical Injury	46	17%	13% (6 of 46)	87% (40 of 46) • 36 resolved-No abuse or neglect found
Abuse	36	13%	28% (10 of 36)	72% (26 of 36) • 15 inconclusive
Exploitation	19	7%	42% (8 of 19)	58% (11 of 19) • 1 resolved-No abuse or neglect found
Missing Person	14	5%	29% (4 of 14)	71% (10 of 14) • 7 resolved-No abuse or neglect found
Serious Medication Error	4	1	0% (0 of 4)	100% (4 of 4) • 2 resolved-No abuse or neglect found
Use of unapproved restraints	1	1	100% (1of 1)	0% (0 of 1)
Other	1	<1	0% (0 of 1)	100% (1 of 1) • Administrative closure
Death	12	4%	N/A	N/A

Serious Report Serious Reportable Incidents & Investigations Q 2

Total Incidents	Number closed	Number substantiated (substantiated & substantiated for neglect)	Percent substantiated	Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)					Percent not substantiated			
337	273 (81%)	51 + 10 = 61	22%	135	32	31	14	49%	12%	11%	5%	Total= 78%

Breakdown of Serious Reportable Incidents Q2

N= 273

Incident Type	Number of Incidents	Percent of total incidents	Percent Substantiated	Percent unsubstantiated (for all reasons)
UEIH	90	33%	2% (2 of 90)	98% (88 of 90)
Neglect	72	26%	54% (39 of 72)	46% (33 of 72)
Serious Physical Injury	57	21%	11% (6 of 57)	89% (51 of 57)
Abuse	33	12%	30% (10 of 33)	70% (23 of 33)

Missing Person	6	2%	17% (1 of 6%)	83% (5 of 6)
Exploitation	12	4%	25% (3 of 12)	75% (9 of 12)
Serious Medication Error	1	<1%	0% (0 of 8)	100% (1 of 1)
Inappropriate use of restraints causing injury	3	1%	67% (2 of 3)	33% (1 of 3)
Suicide Attempt	1	<1%	0% (0 of 1)	100% (1 of 1)
Death	9	3%	N/A	N/A

Serious Reportable Incidents & Investigations Q1

Total Incidents	**Number closed**	**Number substantiated (substantiated & substantiated for neglect)**	**Percent substantiated**	**Number not substantiated (resolved, unsubstantiated, administratively closed, inconclusive)**				**Percent not substantiated**				
309	**274**	**43 + 10 +2**	**21%**	**150**	**26**	**28**	**14**	**55%**	**9%**	**10%**	**5%**	**Total= 79%**

Breakdown of Serious Reportable Incidents Q1

N= 274

Incident Type	**Number of Incidents**	**Percent of total incidents**	**Percent Substantiated**	**Percent unsubstantiated (for all reasons)**
UEIH	100	36%	1% (1 of 100)	99% (99 of 100)
Neglect	61	22%	52% (32 of 61)	48% (29 of 61)
Serious Physical Injury	43	16%	9% (4 of 43)	91% (39 of 43)

Abuse	29	11%	24% (7 of 29)	76% (22 of 29)
Missing Person	13	5%	8% (1 of 13%)	92% (12 of 13)
Exploitation	12	4%	42% (5 of 12)	58% (7 of 12)
Serious Medication Error	8	3%	13% (1 of 8)	87% (7 of 8)
Inappropriate use of restraints causing injury	3	1%	67% (2 of 3)	33% (1 of 3)
Other	3	1%	33% (1 of 3)	67% (2 of 3)
Use of approved restraints	1	<1%	0% (o of 1)	100% (1 of 1)
Death	1	<1	N/A	N/A

- Overall incidents were lower; 338 for quarter two and 288 for this quarter, and the number closed remains high.
- The percentage of overall substantiation of incidents was again remarkably low (21%), Q1, (22%) Q2 and (20%) this quarter
- As noted in the introduction, the level of substantiation for UEIH's was also consistently low (1%), Q1, (2%) Q2 and (4%) this quarter.
- Levels of substantiation for Neglect & Exploitation were significantly statistically higher than UEIH's. This is a typical pattern. The cause for these findings is unclear
- Neglect, as it always has been is the most substantiated Serious Reportable Incident
- There was only one death in the first quarter, nine in the second quarter and 12 this quarter. While this appears to be an upwards trend, the total of 22 through three quarters is not statistically significant. There are typically approximately 32-35 deaths per fiscal year.
- DDS is currently undertaking a rewrite of the definitions, policies and practices with the IMEU. Quality Trust has provided our insights and recommendations on that process guided by these results, and those of our Triage and SRI follow up visits.

Preliminary results from our analysis of UEIH's

As noted earlier, we have been conducting an analysis of a statistically significant number of unplanned hospitalizations from last fiscal Year. Our methodology is based on a tool that looks at relevant issues leading up to the hospitalization, e.g. review of any nursing notes, prior hospitalizations and ER visits that didn't lead to a hospitalization, the discharge documentation from the hospitalization and the investigation of the incident, both by the provider and, when applicable IMEU. The questions we seek to answer are: Were any signs or symptoms missed that lead to the unplanned trip to the emergency room? What diagnosis was made at the hospital? Were discharge recommendations followed? Did they address health issues satisfactorily? What issues were brought out in the investigation? Was the final disposition, e.g. substantiated or unsubstantiated for abuse or neglect as a cause of the unplanned hospitalization? As we have done in the past we are using a 5% confidence interval. Here are some highlights of our findings so far:

- 100% of the hospitalizations reviewed so far had a final disposition of: resolved-no abuse or neglect found. DDS maintains that resolved-no abuse neglect found indicates that no neglect caused the hospitalization. As we have pointed out in our reports, this classification would seem to be duplicative of the classification of unsubstantiated which already exists
- The most numerous symptoms leading to the unplanned emergency room visit were:
    - Pain
    - Lethargy/fatigue
    - Nausea/vomiting
- The most typical initial diagnoses were:
    - Pneumonia
    - Dehydration
    - Sepsis
    - UTI/Kidney issues
- Most admissions lasted from 2-7 days
- Most people reviewed so far had not experienced a hospital admission, or ER visit without being admitted in the three months prior to, or after the one reviewed. This is a significant finding because it reflects a higher level of single admissions, rather than repeat admissions. Within psychiatric admissions a few people typical account for multiple admissions.
- The clear majority of Service Coordinators had completed required monitoring tools concurrent to the admission, but only slightly more than half addressed the issues present in the hospitalization
- A large majority of people experienced symptoms for 24 hours or less prior to admission
- A significant number of provider investigations were accepted by IMEU without requests for more information or significant modification
- We only found a small number of instances where information relevant to the hospitalization was not included in the provider's investigation
- In a clear number of investigations reviewed our analysis corroborates the provider/IMEU investigation
- However, in those with which we disagree we found egregious errors and nursing failures

We have not completed the full review at this time, so these results will be updated, and more reviews are completed. We will release our full and results in a separate report.

HRAC & RCRC Review:

HRAC Review:

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. During the third quarter of fiscal year 2019 DDS provided Quality Trust with the minutes from HRAC meetings held on April 24, 2019, May 22, 2019, and June 26, 2019. Quality Trust did not receive the approved June 29, 2019 HRAC meeting minutes until August 27, 2019.

Based on the minutes provided, the HRAC reviewed 44 human rights issues for 26 people during this quarter.

- 29 issues (66%) were about Long-Term Acute Care ("LTAC") placements
- 8 issues (18%) were about out-of-state residential placements
- 4 issues (9%) were about nursing home placements

- 3 issues (7%) were about other human rights concerns, including those relating to BSP exemption and refusals to go to medical appointments or provide medical documentation to providers.

This quarter, the HRAC rejected placements for not being the least restrictive setting to meet the person's needs on 6 occasions, and it deferred deciding on six occasions because of the need for more information related to the placement. However, in nine occasions this quarter, the HRAC approved a placement without expressly recording within its minutes that it had found the placement to be "the least restrictive and most appropriate settings to meet [the person's] needs (contra DDS HRAC Procedure Section 3(A)(2)(b), emphasis added). DDS should ensure that, in every placement review, the HRAC is considering whether the person can be appropriately served in a less-restrictive environment and recording the related finding in its minutes.

RCRC Review:

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 ("BSP's) of people served by DDA to ensure restrictive controls within them are appropriately justified. These minutes are generally provided by DDS on a monthly basis.

Based on Quality Trust's review, during the third quarter of Fiscal Year 2019:

- RCRC reviewed a total of 150 BSPs for 134 people.
  - All the reviews appeared to be non-emergency reviews of new BSPs (117; 78%) and updated BSPs (33; 22%).

- Of the BSPs reviewed, the vast majority were approved (140; 93%). A subset of these BSPs were approved for 30 days only (2 BSPs), 60 days only (1 BSPs), 90 days only (7 BSPs), and 6 months only (1 BSP).
  - 62 (41%) of the BSPs reviewed 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 approval criteria listed in DDS' RCRC Procedure.[1]
  - 2 (1%) of the BSPs reviewed were approved without clear RCRC answers to one or more of the 8 criteria being included in the minutes.

- 2 (1%) of the BSPs were rejected.

    - 7 (6%) of the BSPs were deferred.
  - All these BSPs that were deferred, rather than rejected, even though the RCRC answered "No" to one or more of the 8 required criteria.[2] More specifically, RCRC found:
    - In at least 3 of these cases, the BSP did not include a rationale for using the restrictive interventions

[1] See DDS Procedure No. 2013-DDA-PR014, Section 3(D)(3), available at https://dds.dc.gov/node/739062, which lists the 8 criteria. 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."

[2] Under DDS Procedure No. 2013-DDA-PR014, Section 3(D)(4)(c), RCRC "shall 'reject' a plan when it does not meet[] the criteria discussed above at [Section 3] D.3" (emphasis added).

- In at least 3 of these cases, the BSP did not include targeted behaviors that were consistent with the person's diagnoses.
- issues consistent with DDA policies.
- In at least 2 of these cases, the BSP did not include benchmarks for reducing restrictive interventions.
- In at least 1 of these cases, the BSP did not include a functional analysis.
- In at least 1 of these cases, the BSP did not include demonstrated review of the data by the psychologist.
- In at least 1 of these cases, the BSP did not include proactive and positive strategies

- The three most common restrictive controls reviewed within the BSPs were the use of psychotropic medications (within at least 146 or 97% of the BSPs), behavioral one-to-one aides (within at least 58 or 39% of the BSPs), and physical restraint (within at least 23 or 15% of the BSPs),

- RCRC reviewed 4 requests for exemption from the requirement of having a BSP. All these requests 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 past recommendations. However, we remain concerned that RCRC may be approving plans that it should be rejecting or deferring. For example, during the last quarter:

- At least 47 BSPs (31%) were approved until the end of the person's current or next ISP year, even though the RCRC minutes also indicated that the BSPs must be revised and re-submitted for a review prior to that time.[3]
- At least 30 BSPs (20%) were approved, even if they referred to a restrictive control for which RCRC required further justification.
- At least 16 BSPs (11%) were approved, even though they referred to a restrictive control that RCRC expressly rejected or deferred.
- At least 3 (2%) of the BSPs reviewed was approved, even though RCRC indicated that one of the required criteria was not met

As we have indicated in our past reports, 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.

Conclusion

During the first three quarters of the Fiscal Year our work advocating for people with intellectual and other developmental disabilities and their families and our data indicate that the District government has:

- Begun a significant retrenchment of IDD spending
- Chosen to limit or not engage in full and frank dialog with stakeholders before initiatives began
- Proposed discontinuing a popular health initiative with the Georgetown UCEDD designed to support provider healthcare services, once again without prior notice to the stakeholders
- Because of this action and associated press coverage a hearing in the Council was held and stakeholders continue to express concern with DDS's outreach and recent developments.

[3] Under the DDS Guidance for RCRC Review of Behavioral Support Plans, available at https://dds.dc.gov/node/803762, BSPs that RCRC approves are supposed to be "acceptable as written and do not require further revision."

New requests for our advocacy support continue to center on what are typically characterized as case management functions. We encounter situations where people with disabilities and/or their families are unhappy with the choices they are offered, and the process used to meet their needs. Most often it is a perceived lack of urgency by provider staff or DDA Service Coordinators that compels people to reach out to Quality Trust. As noted in this report, we continue to advocate for changes to the IMEU policy and hope that strong consideration be given to elevating UEIH's to level one status, and/or that nurses review provider investigations of these incidents.

Last quarter we expressed concern about the reduction in hospitals available for people with disabilities close to where they live with the closure of Providence and United Medical Center. This concern is heightened with the news that the DDA Health Initiative will not be continued and responsibilities transitioned to internal DDS staff members and a new provider. A transition plan was proposed by DDS however meaningful dialogue has occurred with the broad array of stakeholders concerned about this change.

Finally, we note that DDS is implementing cost cutting measures within the IDD service system. Our concern is funding is being reduced at a time when need for expansion has not yet been addressed. We have not seen a long-range strategy from DDS to address the current and future needs of DC residents with disabilities. Specific concern is focused on how the system will balance the needs of former residents of Forest Haven in their later years and with an influx of people with Autism who are likely to increase costs significantly. It is important that planning for these realities begin sooner rather than later. We look to DDS to take the lead in preparing the Council and greater stakeholder community for the work ahead in these areas. We also recommend that DDS provide more time for dialog and input from stakeholders.

We remain convinced that District's IDD system is small enough to achieve the goal of delivering high quality supports tailored to the unique needs and preferences of each person, however the current situation does not provide evidence that leadership in the District of Columbia is planning to move beyond the current practice of reactive planning.