Guidance for One PPR

*Revised January 2022*

**Part 1**

**Demographics**

*This guide contains blue hyperlinks to definitions and additional information. Press CTRL and click to go to the linked section of the guide.*

**[Individual Advocacy](#Individual_Advocacy_Service)**

**Part 1 Sections A - H**

Use this section to report [Individual Advocacy Service](#Individual_Advocacy_Service).

**Part 1 Section I – Racial and Ethnic Diversity**

Report the race and ethnicity of individuals served in the column identified as individual number.

Enter the number of individuals served in the identified race and ethnicity categories of the total individuals served in the fiscal year. The number used for total individuals served in the fiscal year should match the number in 1-A.3

Part 1 Sections J – O --**Interventions Benefitting Groups**

Use this section to report on [Group Advocacy Services](#Group_Advocacy_Services).

Line 1.J.1: “Group cases/projects still open at October 1.”

These are the projects that the P&A continued to work on during the past fiscal year that served groups rather than individuals. Report the number of cases/projects opened in a previous fiscal year that the P&A continued work on during the fiscal year of report”. DO NOT count open cases/projects for which no work was performed during the fiscal year covered by this report. Multiple counts are not permitted.

These projects should employ one of the four intervention strategies listed in “Section 1.N” ([abuse and neglect investigation](#Investigation); [systemic litigation](#Systemic_Litigation); [educating policymakers](#Educating_Policy_Makers); and [other systemic advocacy](#Other_Systemic_Advocacy)) with the intent of achieving a result(s) measurable using one or more of the performance measures listed in “Section 3.A: [End Outcomes](#End_Outcome)”.

Line 1.J.2: “New group cases/projects opened during the year.”

Report the number of new group cases/projects. These projects should employ one of the four intervention strategies listed in “Section 1.N” ([abuse and neglect investigation](#Investigation); [systemic litigation](#Systemic_Litigation); [educating policymakers](#Educating_Policy_Makers); and [other systemic advocacy](#Other_Systemic_Advocacy)) with the intent of achieving a result(s) measurable using one or more of the performance measures listed in “Section 3.A: [End Outcomes](#End_Outcome)”.

Line 1.J.3: “Total group cases/projects worked on during the year.

Add lines I1 and I2 for Total group cases/project for year. It should include group cases/projects from the previous fiscal year as well as any opened in current fiscal year.

Line 1.J. 4: “Total group cases/projects as of September 30 (Carry over to next FY)”

Report the number of group cases/projects your P&A plans to leave open AND perform work on during the fiscal year following the one covered by this report.

Line 1.J.5: “Group cases/projects targeted at serving racial/ethnic minority(ies)”

Report the number of group cases/projects:

a). where the individuals potentially impacted are disproportionately part of an ethnic or racial minority and/or

b). that were opened to address issues of concern to racial/ethnic communities identified through your P&A’s outreach and/or the priority setting process.

Examples of such projects/cases are to be included in Part II [Results Narratives](#Results_Narrative).

Example 1: The P&A opens a group project to serve a predominantly African-American school district. Example 2: The P&A leads initiative to produce school discipline notifications in languages other than English for parents.

Line 1.J.6: “Total number of individuals potentially impacted by line I.A.3 cases/projects”

This section asks you to report on the number of individuals affected by your group activities. Report the number of individuals potentially impacted by the group cases/projects included in this section. Count the number of people who could benefit from the End Outcome(s) being pursued or which have been achieved during the fiscal year covered by this report. AIDD recognizes that some P&As want to report each time an individual is impacted by P&A advocacy, when the same individual is affected separate times by different P&A projects. However, at this time, AIDD is only collecting information on the number of individuals served. To serve AIDD reporting needs, these numbers need to be an unduplicated count.

AIDD also realizes that a project’s impact may affect people with other disabilities than DD. However, as this report is focused on the PADD grant, AIDD requests P&As limit their counts to people with intellectual and developmental disabilities that fit the eligibility criteria for the PADD grant for the purpose of this report.

If less than the total DD population is affected, combine as many projects/cases as necessary to achieve the highest number possible WITHOUT counting any individual more than once. Start with the cases/projects with the largest number of potential beneficiaries and work down until you have a number that you think fairly represents the number of people who may be impacted by your group projects/cases the. ***Under no circumstances is the number to exceed the number of people with intellectual or developmental disabilities in your state or territory.***

The explanation for the “potentially impacted” impact number should be reported in the Results Narrative in Part 2.

Section 1.K Problem areas/Complaints of Groups Served

Report the problem areas addressed by the case/project. A project/case **may** address more than one problem area/complaint. The system does not require validation between any totals in K-P with the number of activities in J.

Section 1.L Living Arrangements Targeted by Group Interventions

If many of the individuals in the group being served by a group project/case live in a particular type(s) of living arrangement, report it here. More than one living arrangement may be used. For example, if two living arrangements are being targeted by a group case/project, count “1” in each of the two living arrangements.

If the individuals in the group being served by a group project/case DO NOT live in any particular living arrangement or their living arrangements are indeterminable, count “1” under “Not Applicable” for each project/case where this is true.

**Example:** The P&A is working to ban prone restraints in ICFs. Report “1” in the ICF column for that project.

**Example**: The P&A leads a project focusing on education services for prisoners under 21 with I/DD. The P&A may choose to report “1” in Jails, “1” in State Prisons and “1” in Juvenile Detention Centers for that project.

Section 1.M Reasons for Closing Group Cases/Projects

A group case/project being closed that achieved a result(s) measurable using one or more of the performance measurements in “Section 3.A: End Outcomes” is counted under “Concluded Successfully”.

A group case/project being closed that DID NOT achieve a result(s) measurable using one or more of the performance measurements in “Section 3.A: End Outcomes” is counted under “Concluded Unsuccessfully”.

A project which is closed before work is completed due to a decision by someone other than the P&A (e.g., named plaintiffs decide not to participate; community group seeking change disbands) is counted under “Other”. **This option should be used sparingly and documentation of why it is being used should be maintained and available to share with AIDD if needed.**

**Only report CLOSED projects in this section. If a project is carrying on to the next year, do not report it as “Other” or anywhere else in this section**

Section 1.N Intervention Strategies Used in Group Advocacy Cases/Projects

Report the intervention strategy ([abuse and neglect investigation](#Investigation); [systemic litigation](#Systemic_Litigation); [educating policymakers](#Educating_Policy_Makers); and [other systemic advocacy](#Other_Systemic_Advocacy)) used in each case/project. You may select more than one per project.

Section 1.O Age Ranges Targeted by Interventions for Groups

If a high number of the individuals in the group being served by a group project/case are in a particular age range, report it here. More than one age range may be used. For example, if two age ranges are being served by a group case/project, count “1” in each of the two age ranges.

**Example:** P&A brings a class action lawsuit to achieve better EPSDT service provision. The P&A would report “1” in each of the age ranges below for that project.

|  |  |
| --- | --- |
| **Focus** | **Number** |
| 1. Group Cases/Projects Focused on Children Approximately 0-2 yrs. old | 1 |
| 2. Group Cases/Projects Focused on Children Approximately 3-5 yrs. old | 1 |
| 3. Group Cases/Projects Focused on Young People Approximately 5-10 yrs. old | 1 |
| 4. Group Cases/Projects Focused on Young People Approximately 11-23 yrs. old | 1 |

If the individuals in the group being targeted by a group project/case **ARE NOT** in a particular age range or their age ranges are indeterminable, count “1” under “Not Applicable”.

Section 1.P Race/Ethnicity of Groups Served

If a disproportionately high number of the individuals in the group being served by a group project/case are of a particular race and/or ethnicity, report it here. More than one race/ethnicity category may be used. For example, if two race/ethnicity categories are being targeted by a group case/project, count “1” in each of the two race/ethnicity categories.

Report the number of group cases/projects:

a). where the individuals potentially impacted are disproportionately part of an ethnic or racial minority and/or

b). that were opened to address issues of concern to racial/ethnic communities identified through your P&A’s outreach and/or the priority setting process.

**Example:** The P&A opens a group project to improve transition plans in a predominantly African-American school district. Report “1” for “Black/African American” for that project.

**Example**: The P&A leads initiative to produce school discipline notifications in languages other than English for parents who are immigrants. Most parents who need this notification at that school are Asian or Latino. Report “1” for Hispanic/Latino (of any race) AND “1” for Asian.

If the Race/Ethnicity of the Groups are unknown, record project as unknown.

**Part 2**

**Statement of Goals and Priorities**

**Section 2.A - Report on FY 2022 Statement of Goals and Priorities**

This section is where you report on the previous year’s (2021) SGP. The goals and priorities from the previous year cannot be changed in this document. Agencies would have to revise the previous year’s SGP to make changes to this section.

Subsection2.A.1: [Goals](#Goal_Statement)

The goal numbers and goal statements for this subsection are to be imported from Section 3.C of the Statement of Goals and Priorities for the fiscal year covered by this report (2021). The system will do this automatically.

Line 2.A.2: [Priorities](#Priority)

The priority numbers and priorities for this subsection are to be imported from Section 2.C of the Statement of Goals and Priorities for the fiscal year covered by this report (2021). The system will do this automatically.

Line 2.A.3 Strategies Used to Implement Goals and Address Priorities

This subsection is NOT imported from Section 2.C. Report the strategies that were **actually used** in the fiscal year covered by this report, **not** the ones you plan to use in the coming year. More than one strategy can be reported.

Line 2.A.4 Extent to Which Goal was Achieved

Report in this subsection according to the following options:

* **“Not Achieved”:** If a P&A stops working on a goal and removes it from its list of goals without achieving any results measurable using one or more of the performance measurements listed in “Section 3.A: [End Outcomes](#End_Outcome)” in any fiscal year the goal was active, “Not Achieved” is to be selected.
* “**Partially Achieved”:** If a P&A achieves a result, during the fiscal year covered by the report, which is measureable using one or more of the performance measurements listed in “Section 3.A: End Outcomes”, for one but not all of the priorities under a goal, “Partially Achieved” should be selected.
* **“Achieved”:** If a P&A achieves a result, during the fiscal year covered by the report, which is measurable using one or more of the performance measurements listed in “Section 3.A: End Outcomes” for each of the priorities under a goal, “Achieved” should be selected.
* **“No Result This Year”:** If a P&A stops working on a goal and removes it from its list of goals without achieving any results measurable using one or more of the performance measurements listed in “Section3.A: End Outcomes” during the fiscal year covered by the report but had reported results in a previous fiscal year, “No Result This Year” should be selected. Or, if a P&A does not achieve results measurable using one or more of the performance measurements listed in “Section 3.A but will continue working on the goal in the next fiscal year, “No Result This Year” should be selected.

Line 2.A.5 Stage of Implementation

Choose the option that most closely fits the stage of goal implementation for each respective goal.

Line 2.A.6 Results Narratives

This subsection should incorporate narratives relating to stated goals and priorities.

# DEEP DIVE: What is a Results Narrative?

A results narrative is a story which presents relevant information pertinent to each goal and its priorities about an individual or group case/project which is being pursued or was pursued with the intent of achieving a result/outcome.

A results narrative is a story which presents relevant information pertinent to each goal and its priorities about an individual or group case/project which is being pursued or was pursued with the intent of achieving a result/outcome measurable using one or more of the ten performance measurements in the End Outcomes section of the PPR (See Part e measurable using one or more of the ten performance measurements in the End Outcomes section of the PPR (See Part III A of the FY 2015 PADD SGP & PPR). The results narrative documents **P&A outcomes** for technical assistance service requests, cases and projects and tell the stories about how the outcomes were achieved.

The results narrative provides an explanation to the AIDD reviewer of the P&A’s progress for the year. AIDD will assess the PPR for the following:

* Activities implemented under a goal and related to the priorities (e.g., what did the P&A do as activities that worked towards achieving the goal and meeting the priorities?)
* Results achieved for the goal (e.g., what were the results of the P&A activities? Are the results consistent with the goal statement?)
* Sufficient qualitative (e.g., stories) and quantitative (e.g., numbers) that adequately explains what the P&A has done for the year related to the goal and priorities and substantiates the results achieved.
* Barriers to achieving goal, if it has not been achieved.
* The extent to which unserved or underserved individuals or groups, particularly from ethnic or racial groups or geographic regions (e.g., rural or urban areas) were the target of assistance or service.

Please write concise narratives that show the effect of the P&A’s work. Any one example should not exceed two pages. The narrative does not need to exhaustive. Rather, it should highlight the most powerful parts of the P&A’s work on a goal.

P&A work that does not fit the definition in the previous paragraph may be reported in “[Other Qualitative Narrative](#Qualitative_Results)” sections of the PPR.

If you would like more in-depth information about Results Narratives, Goal Statements, and the Tier 1 Review Tool, please see Appendix 2.

# HOW TO COMPLETE A RESULTS NARRATIVE OF P&A ACTIVITIES AND ACCOMPLISHMENTS GRID

Goal Number: Number assigned to goal from the SGP

Priority Number: Number assigned to priority/priorities from the SGP

Collaborators: If relevant, list other organizations that worked with the P&A to achieve this priority. If listed, the collaboration between the P&A and other agency should be significant, with work under the priority achieved by a shared strategy between organizations.

Underserved/Unserved/Minorities Targeted

Check “yes” if the technical assistance service request, case or project was or is being pursued as a result of responding to the needs of a particular minority group/community. This could be because the individuals being served fall into one of these categories or it could because the issue being pursued was identified as being important in the priority setting process by individuals who fall into one of these categories.

Story/Narrative:

The story/narrative should cover the following:

* Describe the problem presented, what the P&A did and what was accomplished
* Describe the target population
* Describe how targeted unserved/underserved minority population is/was served if applicable
* Describe next steps, if applicable

The above story content must:

* Provide enough information to make it clear the advocacy described falls under the priority or priorities identified.
* Provide enough information in the narratives to demonstrate the right performance measure(s) was chosen for the activities being reported.
* Provide enough specificity in the narratives to affirm the [outcome](#Outcome) was achieved and the P&A had a role in achieving it.
* Describe who or what is represented by the number reported in outcome measure. This is particularly important.
* A P&A should avoid overstating the number people who benefitted from their advocacy.
* A P&A should be prepared to explain how it arrived at the numbers it reports if asked by AIDD and the best way not to be asked is to be clear in your narrative and to be conservative and reasonable in any estimation that is required.
* Spell out acronyms the first they are used in the Results Narrative.
* Avoid including any personal identifying information (PII) unless you have the client’s consent in writing.

Performance Measurement and Number

* Performance measurements: The performance measurements to be inserted in the table below must come from Part III of the PADD SGP and PPR. You will be able to choose them from the drop-down selection box. Include one or more of the End Outcomes achieved during the fiscal year covered by this report as a result or partial result of the “[substantive work](#Substantive_Work)” (defined in the Definitions Section of the 2015 PADD SGP & PPR) and described in the above narrative/story. Other performance measurements from Part III are to be included as well.
* Number: is the number of people potentially impacted by a result achieved as described by performance measure to the left of the number.

*Choose performance measures from Part 3.A here for activity described above in the Results Narrative.*

(Part3.A End Outcomes of P&A Activity)

|  |  |
| --- | --- |
| **Performance Measurement** | **Number** |
| 1. People with disabilities who are provided with appropriate community based services resulting in community integration and independence. |  |
| 1. People with disabilities who accessed benefits. |  |
| 1. People with disabilities who live in a healthier, safer or otherwise improved environment. |  |
| 1. People with disabilities who were able to stay in their own home. |  |
| 1. People with disabilities who work in safer and more humane conditions. |  |
| 1. People with disabilities who go to school in safer and more humane conditions. |  |
| 1. Students with disabilities who stayed in school. |  |
| 1. Children with disabilities receiving appropriate services in most integrated settings. |  |
| 1. People with disabilities who had their other rights enforced, retained, restored and/or expanded. |  |
| 1. Public and private places/services made more accessible. |  |

**Section 2.B – Priority Setting Process**

Complete this section by providing a thorough description of how the P&A conducts priority setting process (e.g., methods) used to develop the goals and priorities for the fiscal years covered in your multiyear plan. Revise the sections based on public input each year with the idea that major changes will be made when it is time for a new multiyear plan. PADD SGP & PPR reporting platform has all the prompts and instruction necessary for the completion of this section.

# DEEP DIVE: DATA-DRIVEN STRATEGIC PLANNING

The SGP template provides fields for describing data-driven strategic planning both on a periodic and annual basis, including:

* Means for conducting data-driven strategic planning to include public input
* Efforts for ensuring diversity in the data-driven strategic planning process
* Summary of Results from the data-driven strategic planning, which should provide a summary of the findings and identification of the major issues in the State/Territory (this should paint of picture of needs in the State/Territory based on the information collected by the P&A)
* How the data was used to Develop P&A Goals and Priorities (this section should provide the rationale for the goals and priorities based on the needs identified in the State/Territory. There should be a direct relationship between the goals and priorities and the needs identified based on the data collected and/or reviewed and feedback from a wide range of stakeholders).

**Section 2.C – Current Year Statement of Goals and Priorities**

**This section allows you to edit your goals and priorities for the next fiscal year. Check the box to indicate if there are changes or no changes to the SGP from prior year. If there are changes from the prior year, the system will give you the prompts below.**

[Goal Statement](#Goal_Statement): A goal statement is a written description of something your P&A wants to accomplish through allowable activity with PADD funding. It should be written in such a way as to encompass all of the priorities listed underneath it. Goals of a P&A to be included here are ones that were developed as a part of their mandated goal and priority setting process and are to be measurable using one or more of the performance measures listed in 2.C from FY 2017 PPR utilizing the new system.

# DEEP-DIVE**: GOAL STATEMENTS**

**A goal statement is a general but measurable declaration that describes a future state and gives the general direction, purpose or intent of what should be achieved. A goal statement explains the end result or specific desired outcome but in measurable and attainable terms. A goal should include a description of the result and the entity/group for which the result applies.**

**Goals should ultimately be achievable:**

A measurable goal is something that you can actually measure to determine whether you're getting closer to your goal or further away from it.

* Measureable goals can indicate the actual impact or the effect the P&A is trying to achieve.
* They can include actual measures, such as percentages, rates, ratios, and/or timelines.

It is important for the individuals at a P&A involved in the priority setting process to review the sample goals and priorities included with this guidance to gain an understanding of how to write goals and priorities.

It is recommended P&A develop a minimum of 3-5 goals.

**Example One:** The following is one example of a narrowly drawn goal. See the appendix section for additional examples.

* Goal A: Improved decision making outcomes for people with intellectual and/or developmental disabilities of all ages by maximizing their capacity to participate in and ultimately direct decision making processes in their lives. This will happen when others recognize and accept their capacity and formal and informal supports are provided to maximize their participation and control in the decision making process.

**Example Two:** Here is an example of a goal that serves as an umbrella for a broader range of issues.

* Goal B: Improved access to services and physical accessibility for individuals with intellectual or developmental disabilities, particularly individuals from underserved or language and ethnic distinct communities, as well as assisting individuals who have claims under the Americans with Disabilities Act (ADA) regarding access to services and programs in enforcing, retaining or restoring their rights.

Line 2.C.2 Priorities:

Use one priority row for each PADD related priority under a goal. Add as many priority rows as needed.

Priority Number: Priority numbers are assigned by the system.

Priority: A priority as used here is something under a goal that is more urgent or important than others things thus taking precedence. They are to be used to narrow what a P&A will seek to accomplish under a goal. Priorities are to be written in a way that results achieved will be observable and measureable using one or more of the performance measurements listed in “Part 3.A: End Outcomes” of the PADD SGP & PPR (Part I.A of the Model PPR).

**Example Three:** The following are three priorities that correspond with the narrowly drawn goal in Example One above. See the appendix section for additional examples.

* Priority 1 – Improve the availability, feasibility, and desirability of supported decision making models that increase power and choice of individuals and reduce the reliance on surrogate decision making models, like guardianship, which should be the decision making option of last resort.
* Priority 2 – Increase acceptance of and participation in supported decision making models by medical, legal, educational, and social service providers who presently request or even require people have surrogate decision makers appointed in order to access services.
* Priority 3 – Enforce and expand existing requirements that guardians incorporate the expressed interest of the people they support by incorporating supported decision making models into the guardians’ fiduciary duties in order to increase the decision making authority and capacity of people they serve.

**Example Four:** The following are four priorities that fall under the umbrella of the more broadly written goal in Example Two used above. See the appendix section for additional examples.

* Priority 4 - Increase and maintain affordable, accessible housing.
* Priority 5 - Improve disability access and reduce discrimination in private, public and government programs and services so that all people with disabilities are able to use them effectively.
* Priority 6 - Address disparities in access to services and supports from regional centers for people with intellectual and developmental disabilities from language and ethnic-distinct communities.
* Priority 7 - Enforce rights by ensuring that individuals with disabilities have access to courts, administrative agencies and legal services by responding to proposed constraints on access through amicus briefs or regulatory comments as needed.

Line 2.C.3 Strategies Used to Implement Goals and Address Priorities

Predict (for informative, not binding purposes) the strategies that **will be used** in the fiscal year following the one covered by this report, not the ones that were used during the period covered by this report.

Line 2.C.4 Rationale for adding/changing a goal

If you add or change a goal, provide the reason.

Line 2.C.5 Rational for adding/changing a priority

If you add or change a goal, provide the reason.

This section should include activities related to supplemental funding to expand disabilities network’s access to COVID-19 vaccines and the public health workforce.

Guidance for reporting on activities related to supplemental funding to expand access to COVID-19 vaccines

Grantees will report on any of the service activities listed in the chart below that were implemented using the CDC funding from April 1, 2021 through September 30, 2022. All narrative sections (narrative, successes, challenges, and the questions 1 - 12) are limited to 500 words each.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Service Activity** | 1. **Number of People Served** | 1. **Narrative** | 1. **Successes** | 1. **Challenges** |
| 1. Education about the importance of receiving a vaccine | Provide the following:   * Number of people with disabilities reached by your education activities * Number of all other people[[1]](#footnote-2) reached by your education activities | Describe the type of education activities conducted (e.g., one on one assistance, brochures/pamphlets/ fliers, social media postings, social stories) | Describe the most successful/effective education activities implemented | Describe challenges that limited your ability to educate others about the importance of the vaccine |
| 1. Identifying people unable to independently travel to a vaccination site | List the number of people unable to independently travel to a site | Describe:   * The strategy to identify people unable to independently travel to a vaccination site * The most commonly cited reasons for why they couldn’t travel to the site | Describe successes achieved as a result of identifying people unable to independently travel to a site (e.g., were such individuals able to get vaccinated at an alternative site) | Describe challenges that limited your ability to identify people unable to independently travel to a site |
| 1. Providing technical assistance (TA) to local health departments or other entities on vaccine accessibility | List the number of local health departments or other entities assisted with TA on vaccine accessibility | Describe the type of strategies/TA activities to assist local health departments or other entities on vaccine accessibility | Describe successes achieved as a result of TA activities provided to local health departments | Describe challenges that limited your ability to provide technical assistance to local health departments or other entities on vaccine accessibility |
| 1. Helping with scheduling a vaccine appointment | List the number of people helped in scheduling vaccine appointments | Describe the type of activities used to assist people in scheduling vaccines | Describe successes achieved as a result of assistance provided to help schedule vaccine appointments | Describe challenges that limited your ability to help with scheduling a vaccine appointment |
| 1. Arranging or providing accessible transportation | List the number of people assisted with accessible transportation to a vaccination site | Describe the type of activities used to assist people with accessible transportation to a vaccination site | Describe successes achieved as a result of accessible transportation activities | Describe challenges that limited your ability to arrange or provide accessible transportation |
| 1. Providing companion/personal support | List the number of people assisted with companion/personal support to receive vaccines | Describe the type of activities to provide companion/personal support services for people to receive vaccines | Describe successes achieved as a result of providing companion/personal support services for people to receive vaccines | Describe challenges that limited your ability to provide companion/personal support |
| 1. Reminding people of their second vaccination appointment if needed | List the number of people who needed and received a reminder of their second vaccination appointment | Describe the type of activities to provide people with reminders on their second vaccination appointment | Describe successes achieved as a result of providing reminders to people on their second vaccination appointment | Describe challenges that limited your ability to provide people reminders on their second vaccination appointment |

1. **Overall outcome: Number of people vaccinated as a result of implementing one or more of the service activities (number):**

Provide:

1. The number of people with disabilities vaccinated as a result of implementing one or more of the service activities
2. The total number of all other people vaccinated as a result of implementing one or more of the service activities
3. **Collaboration with ACL partners (ADRCs, AAA, CIL, DDC, P&A, UCEDD) (narrative):**

Describe the nature of collaboration and joint activities with ACL partners, including successes and challenges in your collaboration efforts

1. **Collaboration with other community-based organizations (narrative):**

Describe the collaboration and joint activities with other community-based organizations, including successes and challenges in your collaboration efforts

1. **Overall lessons learned (narrative):**

Describe the leading key lessons learned, as a result of, your overall implementation activities

1. **Recommendations for future activities (narrative):**

Provide recommendations for ACL to consider that will maximize the impact of future responses to disasters or pandemics.

Guidance for reporting on activities related to supplemental funding to expand the Public Health Workforce

On an annual basis, P&As will report on activities undertaken from March 1, 2022 through September 30, 2024. Provide a written summary on the number of full-time equivalents (FTE)s funded, type of public health professional(s) hired, and the activities they are engaged in to advance public health. The type of health professionals may include:

* Case investigator,
* Contract tracer,
* Social support specialist,
* Community health worker,
* Public health nurse,
* Disease intervention specialist,
* Epidemiologist,
* Program manager,
* Laboratory personnel,
* Informaticians,
* Communication and policy experts, and/or
* Other positions as may be required to prevent, prepare for, and respond to COVID-19.

If you would like more in-depth information about Results Narratives, Goal Statements, and the Tier 1 Review Tool, please see Appendix 2.

**Section 2.D – Description of P&A Operations**

**This section is required by the DD Act regulations.** Please fill out Parts 1-2 to comply with federal requirements. Part 3 is optional as that information is collected at other points in the report.

This description must include the System’s processes for intake, internal and external referrals, and streamlining of advocacy services. If the System will be requesting or requiring fees or donations from clients as part of the intake process, the SGP must state that the system will be doing so.

Line 2.D1: Describe P&A Operations

Describe how the P&A operates including information about how the PADD program is coordinated with other P&A programs, as well as the process for intake, internal and external referrals and streamlining of advocacy services if not described elsewhere in the PPR. If this information is provided elsewhere, refer to the appropriate section.

Line 2.D2: Requesting or requiring fees from clients

Indicate if the P&A will be requesting or requiring fees from clients as part of intake process.

Line 2.D.3: Collaboration and Coordination

3.a Describe P&A collaborations with others in the state, including the DDC and the UCEDD if not covered in narratives. If covered in narratives, refer to appropriate narrative by the section and goal where it can be found in the PPR.

3.b Describe how the P&A is reducing duplication of service and overlap of services and sharing of information if not covered in narratives. If covered in narratives, refer to appropriate narrative by the section and goal where it can be found in the PPR.

EXAMPLES OF A “SGP GOAL GRID”, “SGP REPORTING GRID”, &

“RESULTS NARRATIVE GRID

**SGP GOAL GRID**

|  |
| --- |
| **1. Goal Number**: **Goal Statement**: |

|  |  |  |
| --- | --- | --- |
| **2. Priorities** *(Add rows below if needed)* | | |
| *#* | *Priority* | |
|  |  | |
|  |  | |
|  |  | |
|  |  | |
| **3. Strategies to Be Used to Implement Goal and Address Priorities** *(Check all that apply below)* | | |
| □ Collaboration | | □ Systemic Litigation |
| □ Rights-Based [Individual Advocacy Services](#Individual_Advocacy_Service) | | □ Educating Policy Makers |
| □ Investigations of abuse and neglect | | □ Other Systemic Advocacy |
| □ [Monitoring](#Monitoring) | | □ [Training](#Training)/[Outreach](#Outreach) |

|  |
| --- |
| **4. Rationale for adding/changing goal** |
|  |
| **5. Rationale for adding/changing priorities** |
|  |

**SGP REPORTING GRID**

|  |
| --- |
| **1. Goal Number**: **Goal Statement**: |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **2. Priorities** *(Add rows below if needed)* | | | | | |
| *#* | *Priority* | | | | |
|  |  | | | | |
|  |  | | | | |
|  |  | | | | |
|  |  | | | | |
|  |  | | | | |
| **3. Strategies Used to Implement Goal and Address Priorities** *(Check all that apply below)* | | | | | |
| □ Collaboration | | | | □ Systemic Litigation | |
| □ Rights-Based Individual Advocacy Services | | | | □ Educating Policy Makers | |
| □ Investigations of Abuse and Neglect | | | | □ Other Systemic Advocacy | |
| □ Monitoring | | | | □ Training/Outreach | |
| **4. Extent to Which Goal was Achieved** *(Check one below)* | | | | | |
| □ Not Achieved | | □ Partially Achieved | □ Achieved | | □ No Results This Year |

|  |  |  |  |
| --- | --- | --- | --- |
| **5. Stage of Implementation** *(Check one below)* | | | |
| □ Planning | □ Initiation | □ Implementation | □ Outcome/Fully Integrated |

**Results Narrative Grid**

*Technically, the last section of the SGP Reporting Grid*

**6. Results Narrative**

*List goal and priority #(s) addressed in the activity described in the narrative below.*

|  |  |  |
| --- | --- | --- |
| Goal #(s): | Priority #(s): | |
| Collaborator(s): | | |
| Underserved/Unserved/Minorities Targeted? ☐ Yes ☐ No *(If yes, describe in narrative)*. | | |
| <Narrative Headline>  <Story/Narrative>  *Choose performance measures from Part III here for activity described above in this Results Narrative* | | |
| **Performance measurement** | | **Number** |
|  | |  |
|  | |  |
|  | |  |

**Part 3**

**Results of P&A Activity**

**Section 3.A End Outcomes of P&A Activity by Intervention Type**

This section gives summary, quantitative data about how the P&A helped people with disabilities exercise their civil, human and legal rights. These numbers are important to show real impact of the P&A’s work as a federal program.

The system asks users to input how many people benefited as described in each Performance Measurement by intervention type. Populating the table below will be automatically transfer totals of the End Outcomes by P&A Activity Table to the first table in Section III A.

For example, for End Outcome #2, report the number of people with disabilities who accessed benefits through technical assistance, individual advocacy, abuse and neglect investigation, systemic litigation, educating policy makers or other systemic advocacy.

For each end outcome, each count for an intervention type should not exceed the number of people with intellectual or developmental disabilities in your state or territory. **To standardize the results, P&As will use 1.58% as the estimated percentage of people with developmental disabilities in the state/territory.**

Example: state’s DD population is 100,000. P&A must report < 100,000 for each intervention type in End Outcome 2.

AIDD understands that through different forms of the P&A’s work, the P&A may affect the same person multiple times. **THE TOTAL NUMBER FOR EACH PERFORMANCE MEASUREMENT MAY EXCEED THE TOTAL DD POPULATION.**

**ACCEPTABLE Example:** A state’s DD population is 100,000. If the P&A reports that the total population with I/DD was affected in two types of interventions, systemic litigation and educating policy makers for end outcome 2, the total for End Outcome 2 will be at least 200,000 and greater than the DD population. This is acceptable.

**UNACCEPTABLE Example**: A state’s DD population is 100,000. P&A reports 125,000 people benefited from systemic litigation in End Outcome 2. This is unacceptable. The number must be less than 100,000.

For DAD users the reports necessary to complete these tables will be available in the DAD Report Generator. P&As are responsible for having their staff accurately complete the relevant fields in their advocacy records prior to running the reports and inserting the data in the AIDD PPR/SGP platform

Section 3.B Overview of How Many People with Disabilities Served

This section is designed to provide overall results for the P&A, including both individual and group advocacy efforts. This section captures the number of individuals served, the number of [abuse and neglect investigations](#Investigation), [provisions](#Provision) in law modified or prevented, or [provisions](#Provision) in ordinances modified or prevented.

B.1: Number of individuals receiving individual advocacy/self advocacy case level services

B.2: Number of investigations both individual and on behalf of groups

B.3: Report all individuals receiving information, technical assistance or referral services. This number may exceed the number of people with ID/DD in the state.

B.4: Report all individuals trained by the P&A in the year.

B.5: Number of individuals with disabilities impacted by systemic or class action litigation

B.6: Number of individuals with disabilities impacted by non-litigation systemic advocacy

B.7: Report the number of individuals for whom the P&A was not able to provide a higher level of service.

Section 3.C Individual Advocacy

Report results achieved through individual advocacy including [self-advocacy assistance](#Self_Advocacy_Assistance), [limited advocacy](#Limited_Advocacy), [administrative remedies](#Administrative_Remedy), [negotiation](#Negotiation), [mediation](#Mediation), [alternative dispute resolution](#Alternative_Dispute_Resolution), and/or [litigation](#Litigation).

C.1: Number of individuals with individual advocacy/self advocacy case level services closed with the reason for closing being objective was met/partially met

C.2: Number of individuals with individual advocacy/self advocacy case level services that has the problem area access to administrative or judicial processes selected

C.3: Number of closed individual advocacy/self advocacy case level services that with the reason for closing being objective was met/partially met

Section 3.D Investigations of Abuse and Neglect

Report results of [investigations](#Investigation) of abuse and neglect on behalf of individuals.

Sections 3.E Monitoring [PADD/PATBI/PAAT]

Users will be prompted to enter facility name, type, capacity, location and number of visits to the facility during the fiscal year. Once a facility is entered into the system, it can be referred to in future years and only need to be added once.

**Other Qualitative Narrative:** Provide a summary of how the P&A approaches PADD monitoring (i.e., specify is the P&A uses scheduled and/or unannounced monitoring or engages in community based monitoring).

Sections 3.F, G, and H

Report on activities taken throughout the year.

For Section 3.G, only report activity conducted in accordance with the limits on federal funding.

Part 3 Other Qualitative Narrative

What is required in each of the narratives in Part III is included in the PPR/SGP platform instructions. Completing this section is **optional** for each section of Part 3.

**PROGRAM SPECIFIC MEASURES**

Enter information specific to PAAT and PAVA programs here.

PAAT

In the specific program measures, a P&A can pick multiple answers for one device. For example, the P&A may help procure device for hearing that assists with participation in recreation.

PAVA

In the specific program measures, monitoring includes activities like polling place surveys.

### Combined Report for ACL P&A Programs

**Part 1**

Public Relations and Outreach

As it may be easier for a P&A to use paper forms to collect and maintain the information in these sections, sample forms [LINK] for this purpose are included in the appendix.

**Part 2**

**Collaborations**

The purpose for this section is to streamline the reporting of major collaborative efforts and avoid duplication in the reporting of activity. Step 1 is to enter the name and description of all major collaborations. Then when writing Results Narratives as a part of reporting on priority implementation in any of the ACL P&A PPRs, it will only be necessary to select name of the collaboration from a dropdown menu when work it contributed to is being described.

Required collaborations include the client assistance program (unless housed within the P&A), long term care ombudsman (unless housed within the P&A), developmental disabilities council, center(s) for excellence (university affiliated program) and any parent training centers. Listing other collaborations is optional but can be very useful in demonstrating the extent and effectiveness of collaborative efforts.

You must enter a minimum of at least 1 collaboration. You may choose to enter in as many collaborations as needed. Also, when you enter data into the ‘Name of Collaboration’ textbox, it will be stored in the ‘Collaborator(s)’ field in the Narrative located in Section 2: Statement of Goals and Priorities, Subsection A: Report on Statement of Goals and Priorities (SGP). **Information entered here will be available for selection from a drop down menu in Section 2 of the report.**

**Part 3**

**Board, Staff, and Advisory Council Demographics**

The reporting platform has all the prompts and instruction necessary for the completion of this section.

If you are housed in state government, you must complete the Advisory Council section or the Board section. Non-profit agencies must complete the Board section. Non-profit organizations who voluntarily maintain a DD Advisory Council may complete the advisory Council section.

**Definitions**

Primary Consumer: an individual with a disability

Secondary Consumer: a family member or guardian of an individual with a disability

**Part 6**

**General Program Information**

Please enter and/or update information for your 1) main office and 2) satellite offices (if applicable). Names of each staff preparer are also entered here.

**Definitions**

*The following definitions are for terms used in this document as well as the AIDD PPR SGP platform.*

**Absolute Unique Visitor** *(pertaining to websites, blogs, etc.)*

The phrase “absolute unique visitor” is a term of art used in Google Analytics and similar applications. It represents the number of different people that visit a particular website or blog during a period of time specified by the user.

**Abuse**

The term “abuse” means any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes but is not limited to such acts as: verbal, nonverbal, mental and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing such an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations, or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue. In addition, the P&A may determine, in its discretion that a violation of an individual’s legal rights amounts to abuse, such as if an individual is subject to significant financial exploitation.

**Administrative Hearing**

An administrative hearing is a case level of intervention where an individual is assisted in requesting, preparing for, or participating in a formal proceeding to challenge a decision within an agency or facility, or between agencies, which does not involve adjudication by a court of law.

**Administrative Remedy**

An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.

**Advocacy activities**

The term “advocacy activities” means active support of policies and practices that promote systems change efforts and other activities that further advance self-determination and inclusion in all aspects of community living (including housing, education, employment, and other aspects) for individuals with developmental disabilities, and their families.

**Alternative Dispute Resolution**

Alternative Dispute Resolution (ADR) describes any process for settling a contested matter outside of the formal judicial process. ADR includes, but is not limited to negotiation, conciliation, mediation, and arbitration. ADR often includes the aid of a third, neutral party to guide the parties to a settlement.

**Areas of emphasis**

The term “areas of emphasis” means the areas related to quality assurance activities, education activities and early intervention activities, child care-related activities, health-related activities, employment-related activities, housing-related activities, transportation-related activities, recreation-related activities, and other services available or offered to individuals in a community, including formal and informal community supports that affect their quality of life.

**Case**

A matter in which a significant service is provided that is intended to benefit one or more eligible individuals with developmental disabilities. A case file must be established and maintained by the P&A in each such matter. Each case must have a documented client goal.

**Capacity building activities**

The term “capacity building activities” means activities (e.g. training and technical assistance) that expand and/or improve the ability of individuals with developmental disabilities, families, supports, services and/or systems to promote, support and enhance self-determination, independence, productivity and inclusion in community life.

**Client**

For the purposes of the PPR (but not necessarily for determining a client-attorney relationship), a client is an individual or group of individuals who meets three criteria: 1) he/she is eligible for the PADD program; 2) a file/service record has been opened which includes at least the name, address, age, race, disability, signed release of information form (if appropriate), the concern or complaint and the goal of the action to be taken; and 3) he/she has been provided at least one significant service.

**Client Objective**

The result(s) a client(s) desires and the P&A has agreed to pursue as documented in a retainer agreement between the client(s) and the P&A.

**Client Objective Met**

The result(s) a client(s) desired and the P&A agreed to pursue as documented in a retainer agreement was achieved, at least in part.

**Closed Case**

The status of a case when the issue has been addressed through the provision of some level of service, the service is no longer needed, or the client is no longer available to address the issue(s).

**Collaboration**

An activity or set of activities the P&A undertakes with a community partner(s) to pursue a shared advocacy goal. For purpose of this report it includes working with federally funded entities identified in the P&A mandates to assure coordination of the activities between the entities and to avoid inappropriate or wasteful duplication of services.  These entities include a state’s or territory’s client assistance program, long term care ombudsman, developmental disabilities council, center(s) for excellence (university affiliated program) and mental health agency.  Reporting on these collaborations is mandatory.

It also includes coalitions, task forces, councils, etc. in which a P&A participates for the purpose of advocating for systemic reform.  These can be ongoing or time limited collaborations.  Reporting on these collaborations is optional.

**Community Residential Setting**

A community residential setting has three or fewer residents and optimizes autonomy, independence, and access to the community in keeping with the new Medicaid Act and Home and Community Based Services regulations.

**Complaint**

The term “complaint” includes, but is not limited to, any report or communication, whether formal or informal, written or oral, received by the P&A system, including media accounts, newspaper articles, electronic communications, telephone calls (including anonymous calls) from any source alleging abuse or neglect of an individual with a developmental disability.

**Culturally competent**

The term “culturally competent,” used with respect to services, supports, and other assistance means that services, supports, or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved.

**Direct Representation**

Legally based advocacy provided pursuant to a retainer agreement between a Client and a P&A. The intervention types employed may include negotiation, administrative hearings, and/or litigation.

**Developmental disability**

The term “developmental disability” means a severe, chronic disability of an individual that:

(1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;

(2) Is manifested before the individual attains age 22;

(3) Is likely to continue indefinitely;

(4) Results in substantial functional limitations in three or more of the following areas of major life activity:

(i) Self-care;

(ii) Receptive and expressive language;

(iii) Learning;

(iv) Mobility;

(vi) Self-direction;

(vii) Capacity for independent living; and

(viii) Economic self-sufficiency.

(5) Reflects the individual’s need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in paragraphs (1) through (5) of this definition, if the individual, without services and supports, has a high probability of meeting those criteria later in life.

**Educating Policy Makers**

A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities.  Our advocacy efforts might be directed at the local, state, or federal level.  Educating these individual makes them aware of how their actions may impact people with disabilities.  Information reported should only include work done in accordance with the limit on federal funding.

**End Outcome**

An end outcome is a quantitative performance measurement that expresses the ultimate benefit to the client.

**Full investigation**

The term “full investigation” means access to service providers, individuals with developmental disabilities and records authorized under these regulations, that are necessary for a P&A system to make a determination about whether alleged or suspected instances of abuse and neglect are taking place or have taken place. Full investigations may be conducted independently or in cooperation with other agencies authorized to conduct similar investigations.

**Goal Statement**

A goal statement is a general but measurable declaration that describes a future state and gives the general direction, purpose or intent of what should be achieved. A goal statement explains the end result or specific desired outcome. A goal should include a description of the result and the entity/group for which the result applies. Goals should be ultimately be achievable.

**Group Advocacy Services**

Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors.

**Group Number Impacted** *(And the “At Least” Method of calculating an estimate)*

A specific unduplicated number of people impacted should be used with a [“number impacted” performance measure](#Number_Impacted_Performance_Measure) when the number is known or a very close estimate is possible based on available data. For instance, you know all of the people on a particular ward of a hospital will benefit but the number of people on that ward varies slightly from day to day. Then a number close to the number usually present on that ward can be used.

If a close estimate is not possible based on available data but the range the number falls within can be determined and supported by available data, a number followed by a plus sign (+) from the following chart should be used in the “number impacted” performance measure. This method of estimation should also be used when a certain number of people could be impacted but it is not clear that they all will be impacted.

If the number is unknown and there is no available data to support the estimation, then a “number impacted” performance measure should not be used.

|  |  |
| --- | --- |
| **Estimate**  **to**  **Put in PPR** | **Range**  **for what the**  **estimate means** |
| 1+ | 1-9 |
| 10+ | 10-99 |
| 100+ | 100-999 |
| 1,000+ | 1,000-9,999 |
| 10,000+ | > 10,000 |

**Inclusion**

The term ''inclusion'', used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enable individuals with developmental disabilities to have friendships and relationships with individuals and families of their own choice; live in homes close to community resources, with regular contact with individuals without disabilities in their communities; enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

**Individual Advocacy Service**

Legally based work on behalf of a client using one or more of the following intervention types: Self-Advocacy Assistance, limited advocacy, administrative remedies, negotiation, mediation/alternative dispute resolution, and/or litigation. For the purpose of this report it does not include investigations which are reported in a separate section.

**Individualized supports**

The term “individualized supports” means supports that: enable an individual with a developmental disability to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life; designed to enable such individual to control such individual’s environment, permitting the most independent life possible; and prevent placement into a more restrictive living arrangement than is necessary and enable such individual to live, learn, work, and enjoy life in the community; and include early intervention services, respite care, personal assistance services, family support services, supported employment services support services for families headed by aging caregivers of individuals with developmental disabilities, and provision of rehabilitation technology and assistive technology, and assistive technology services.

**Information and Referral Service**

Information and referral includes responses to individuals at meetings, one-time telephone discussions, and follow-up mailings of letters, brochures and/or pamphlets per an individual’s request. I&R includes brief written or oral information, such as, generic information about the P&A, including information about additional programs and resources external to the P&A relating to the individual’s service needs and statutory or constitutional rights as a person with a disability. The agency generally would not have personal identifying information about the individuals who request and/or receive I&R services, except for possibly the name, address and telephone number.

**Institutional Living Arrangement**

In keeping with the new Medicaid law, any facility with a minimum of four residents that does not optimize autonomy, independence, and access to the community**.**

**Integration**

The term “integration,” means exercising the equal rights of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.

**Investigation**

An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

**Law** *(see also regulation and policy)*

For the purpose of completing this report law refers to statutory or common law.

**Legal guardian, Conservator, and Legal representative**

The terms “legal guardian,” “conservator,” and “legal representative” all mean a parent of a minor, unless the State has appointed another legal guardian under applicable State law, or an individual appointed and regularly reviewed by a State court or agency empowered under State law to appoint and review such officers, and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, persons acting only to handle financial payments, executors and administrators of estates, attorneys or other persons acting on behalf of an individual with developmental disabilities only in individual legal matters, or officials or their designees responsible for the provision of services, supports, and other assistance to an individual with developmental disabilities.

**Limited Advocacy**

Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.

**Litigation**

Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

**Mediation**

Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.

**Monitoring**

Monitoring includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring mayinvolve using the a P&A’s access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

**Neglect**

The term “neglect” means a negligent act or omission by an individual responsible for providing services, supports or other assistance which caused or may have caused injury or death to an individual with a developmental disability(ies) or which placed an individual with developmental disability(ies) at risk of injury or death, and includes acts or omissions such as failure to: establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; or provide a safe environment which also includes failure to maintain adequate numbers of trained staff or failure to take appropriate steps to prevent self-abuse, harassment, or assault by a peer.

**Negotiation**

Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.

**Number Impacted Performance Measure**

A number impacted performance measure is one that asks for the number of people with disabilities in a group that was the target of a P&A’s advocacy.

**Other Systemic Advocacy**

Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

**Outcome**

An outcome is a quantifiable performance measure expressed in terms of a -any result achieved for a client or group of clients.

**Output**

An output is a performance measure that describes something quantifiable and concrete that is not descriptive of an end result desired by a client or group of clients but rather an incremental or interim step along the way. It can also be used to capture P&A engagement in an on-going intervention.

**Outreach** is an activity that provides targeted information to specific populations regarding the activities of the P&A or one of its programs.

**Performance Measure Menu**

Each advocacy intervention type has an associated list of outcome and output performance measures. It is not expected that a P&A would use every performance measure on every menu.

**Priority**

For purposes of this report, a priority is a subset of and related to a larger goal statement which the P&A plans to work on during the reporting period. Priorities are allocated resources so that a measurable result can be documented. Priorities as established through the SGP serve as the basis for the P&A to determine which cases are selected in a given fiscal year. P&As have the authority to turn down a request for assistance when it is outside the scope of the SGP, but they must inform individuals when priorities are the basis for turning them down.

**Probable cause**

The term “probable cause” means a reasonable ground for belief that an individual with developmental disability(ies) has been, or may be, subject to abuse or neglect, or that the health or safety of the individual is in serious and immediate jeopardy. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect.

**Provision**

For the purpose of completing this report, a provision is a clause in [statute](http://www.businessdictionary.com/definition/statute.html) that explains a specific [condition](http://www.businessdictionary.com/definition/condition.html), effect, implication, [qualification](http://www.businessdictionary.com/definition/qualification.html), or requirement that would result in benefit or detriment to people with disabilities.

**Qualitative Results**

The result of advocacy efforts expressed primarily through a narrative describing what was accomplished and includes the specifics of the [outcomes](#Outcome) and [outputs](#Output) reported in the quantitative results.

**Quantitative Results**

The result of advocacy efforts expressed using outcome or output performance measures.

**Results Narrative**

A qualitative results narrative describes the specifics of what the P&A achieved in response to a direct representation service request or in a group advocacy project in a way that illustrates and humanizes the associated quantitative performance measures. The narrative includes:

* Headline capturing the gist of what follows (optional but helpful to the AIDD reviewer)
* Priority addressed if applicable
* The Results Narratives document (provide story of) how the advocacy elements worked together to achieve outcomes for our clients in a more efficient and coherent way than in the current program performance reports. The story/results narrative:
  + Describe the problem presented, what the P&A did and what was accomplished
  + Give specifics to general terms in performance measures
  + Description of how targeted toward unserved/underserved minority population if applicable
  + Next steps if applicable
  + Mention collaborators and partners if applicable including a cross reference to where a collaboration is described elsewhere in the report (Collaborations Section)
* Completed quantitative performance measures accomplished

**Self-Advocacy Assistance**

Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self-advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.

**Self-determination activities**

The term “self-determination activities” means activities that result in individuals with developmental disabilities, with appropriate assistance, having the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and contribute to, their communities; and support, including financial support, to advocate for themselves and others to develop leadership skills through training in self-advocacy to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

**Significant Service**

Includes the Self-Advocacy Assistance, Limited Advocacy,Negotiation, Administrative Hearings/Alternative Dispute Resolution, or litigation.

**Substantive Work**

Work performed by a P&A that can reasonably be interpreted as having contributed to a result measurable using one or more of the End Outcomes performance measures listed in Part 3.A.

**Standardized Performance Measure**

A standardized performance measure is one that is to be used when doing like activity and reporting like results. For the purpose of this report it refers to both the outcome and output performance measures included in the result sections.

**Systemic change activities**

The term “systemic change activities” means a sustainable, transferable and replicable change in some aspect of service or support availability, design or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

**Systemic Litigation**

Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

**Technical Assistance**

Technical assistance is provided to family members, non-legal guardians, professionals or other advocates in consultation regarding an area of the law in which the P&A has expertise. It is considered a non-client directed activity.

**Tier 1 Review Tool**

The Tier I Review Tool is used by AIDD in the compliance and outcome review process of the SGP and PPR and will be used, in part, to determine whether a P&A needs a higher level of review (Tier II). It is used annually by AIDD staff to conduct high level program compliance and outcome reviews of the P&AA PPR and SGP. The compliance review verifies through review of the PPRs and SGPs that the P&A is compliant with DD Act requirements. The outcome review uses narrative information and measures (data) to evaluate performance based on data analysis. The outcome review focuses on data and narrative results of outcomes/results achieved. The outcome and output data is reviewed for each P&A program and across all P&As programs to understand results.

**Training**

Training is an activity that builds skills and knowledge of target populations. Training may be provided to individuals with disabilities and others.

**Unserved and underserved**

The term “unserved and underserved” includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in community life.

**Part VIII**

**Appendix**

**Sample Forms 1 -Monitoring Visit**

**Employee(s): Name of facility:**

**Facility capacity: County:**  **Date of Visit:**

**Fund (Check all that apply):**

☐COMBO ☐PADD ☐PAIMI ☐PAIR ☐PAVA ☐PABSS ☐PAAT ☐PATBI ☐OVW ☐GF

☐ Other, specify:

**Type of facility:**

☐ Municipal Detention Facility Jail

☐ [Public Institutional Living Arrangement](#Institutional_Living_Arrangement)

☐ State Hospital

☐ State Prison

☐ Other

**Monitoring Performance Measures**

|  |  |
| --- | --- |
| **Performance Measurement** | **Number of** |
| 1. People with disabilities whose living, working and/or other circumstances were monitored by P&A |  |
| 1. Monitoring visits to review living, working and other conditions in segregated settings |  |
| 1. Complaints referred to regulatory agencies or investigative organizations |  |
| 1. Provide the number technical assistance or self-advocacy materials were disseminated (total from reverse side) |  |

Was a health and/or safety issue or other rights violation identified and validated or addressed during the monitoring visit? ☐ Yes ☐ No

Was a health and/or safety issue or other rights violation identified but not validated or addressed? ☐ Yes ☐ No If yes, complete an intake form and submit to case acceptance.

**Form 2 -Training and P&A Presentation**

**Employee(s):**

**Name of Event: Date(s) of Event:**

**Fund (Check all that apply):**

☐COMBO ☐PADD ☐PAIMI ☐PAIR ☐PAVA ☐PABSS ☐PAAT ☐PATBI ☐OVW ☐GF

☐Other, specify:

**Location of Event** (City, State)**:**

**Training Title** (if different from the event):

☐ Yes ☐ No Was this a presentation about DRW to community group?

☐ Yes ☐ No Did this involve a P&A exhibit at conference, community fair, etc.?

☐ Yes ☐ No Was this an advocacy skills training?

☐ Yes ☐ No Was this a rights training?

**Measures from Training and Public Relations Sections**

|  |  |
| --- | --- |
| **Performance Measure** | **Number of** |
| 1. People who report the training enhanced their knowledge and/or skill (was beneficial) at the completion of the training |  |
| 1. Provide number of people who were trained to become active participants in making decisions that affect their lives (only count people with disabilities) |  |
| 1. Provide number of people at the training/presentation? (already a field in DAD training projects) |  |
| 1. Provide the number technical assistance or self-advocacy materials were disseminated (total from reverse side) |  |

**Form 3 - Mass Media Contact Report**

**Employee(s):**

**Was contact related to an ongoing case or project?** ☐ Yes ☐ No

**If yes, which one:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ ☐ Service Request ☐ Project

**If not what was the contact about?**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Fund (Check all that apply):**

☐ PADD ☐ PAIMI ☐ PAIR ☐ PAVA ☐ PABSS ☐ PAAT ☐ PATBI ☐ OVW ☐ GF

☐ Other, specify: \_\_\_\_\_\_\_\_\_\_\_

**Include in PPR for which fiscal year?** \_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Mass media related performance measures**

|  |  |
| --- | --- |
| **Performance Measure** | **Number of** |
| 1. Press releases issued |  |
| 1. Times a P&A representative was interviewed or featured on TV or radio |  |
| 1. Articles about the P&A or its work in external mass media such as newspapers, radio, podcasts, blogs or television |  |
| 1. Articles by the P&A about disability rights issues published in newspapers, books, journals or magazines |  |

**Media contact’s name:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Phone number:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **Email:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Media entity:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Provide URL links to the above if available:**

**Form 4 - Web Platform, Newsletter, and Other Publication Report**

**Employee(s):**

**Include in PPR for which fiscal year:**

**Related Performance Measures**

|  |  |
| --- | --- |
| **Performance Measure** | **Number of** |
| 1. Provide the number of social media followers |  |
| 1. Provide the number of a[bsolute unique visitors](#Absolute_Unique_Visitor) to blogs/web pages where information about the P&A is posted |  |
| 1. Provide the circulation number of the P&A’s newsletter and/or listserv updates |  |
| 1. Provide the number of times a newsletter or other P&A related information was disseminated to people on the P&A’s listserv |  |
| 1. Provide number of links to other disability rights related information sources published on the P&A website |  |
| 1. Provide the number of technical assistance or self-advocacy materials published or revised |  |
| 1. Provide the number of technical assistance or self-advocacy materials were disseminated (Google Analytics + monitoring (Form 1) + training/ P&A presentations (Form 3) |  |

**Provide URL links to the above if applicable:**

# APPENDIX 2

# DEEP DIVE: Why are the Results Narratives important?

* Results Narratives “put a face” on the quantitative performance measures and provide a context for the PPR/SGP reader to understand the meaning of the outcome numbers being reported.
* Results Narratives document how advocacy strategies worked together to achieve outcomes for our clients/constituents in a more efficient, logical and coherent way than in the current program performance reports.
* The Results Narratives will be the primary PPR/SGP source for informing many of the questions and prompts in the Tier I Review Tool used by AIDD to assess the P&A’s progress in implementing its goals and priorities and any outcomes achieved that year. It also helps document P&A compliance with federal requirements.
* A good showing on the Tier I Review potentially makes it less likely a P&A moves to a Tier II Review.

AIDD will use the results narrative to defend the P&A program. Results narrative are also used for budget justifications and providing information to the general public and Congress about P&A activities and accomplishments

# DEEP DIVE: SMART Goals

Goals are the starting point for planning. There are many approaches to writing goals. P&As should aim towards developing goals that are **SMART**:

**S**pecific  
**M**easurable   
**A**ttainable   
**R**ealistic   
**T**imely

**Specific** - A specific goal has a much greater chance of being accomplished than a general goal. To set a specific goal you must answer the six "W" questions:

* Who: *Who is involved?*
* What: *What do I want to accomplish?*
* Where: *Identify a location.*
* When: *Establish a time frame.*
* Which: *Identify requirements and constraints.*
* Why: *Specific reasons, purpose or benefits of accomplishing the goal.*

For example, a general goal would be, "Get in shape." But a specific goal would say, "Join a health club and workout 3 days a week."

**Measurable** - Establish concrete criteria for measuring progress toward the attainment of each goal you set. When you measure your progress, you stay on track, reach your target dates, and experience the achievement that spurs you on to continued effort required to reach your goal. To determine if your goal is measurable, ask questions such as:

* How much?
* How many?
* How will I know when it is accomplished?

**Attainable** - When goals are identified that are most important to the P&A, the P&A begins to figure out ways the goals can be achieved. The P&A develops the attitudes, abilities, skills, and financial capacity to reach them. The P&A begins seeing previously overlooked opportunities to come closer to the achievement of the P&A's goals. The P&A can attain most any goal when steps are planned wisely and when a time frame is established that allows the P&A to carry out those steps.

**Realistic** - To be realistic, a goal must represent an objective toward which the P&A is both *willing* and *able* to work. A goal can be both high and realistic. The P&A can decide just how high the goals should be. But be sure that every goal represents substantial progress. A goal is probably realistic if the P&A truly *believes* that it can be accomplished. Additional ways to know if the goal is realistic is to determine if the P&A has accomplished anything similar in the past or asking what conditions would have to exist to accomplish this goal.

**Timely** - A goal should be grounded within a time frame. With no time frame tied to it there's no sense of urgency. If the goal is to lose 10 pounds, what is the target date for the weight loss? "Someday" won't work. But if the goal is anchored a timeframe, "by May 1st", then work can begin on the goal.

**T** can also stand for **Tangible** - A goal is tangible when it can be experienced in some way. When a goal is tangible, there is a better chance of making it specific and measurable and thus attainable.

# DEEP DIVE: TIER 1 TOOL

**What is the** [**Tier I Review**](#Tier_1_Review_Tool) **Tool?**

The Tier I Review Tool is used by AIDD in the compliance and outcome review process of the SGP and PPR and will be used, in part, to determine whether a P&A needs a higher level of review (Tier II or Tier III). It is one mechanism used by AIDD to review P&As. The current Tier 1 Review Tool is in the appendix.

# DEEP DIVE: CHOOSING CASES FOR NARRATIVES

**How should a P&A determine which individual cases or group advocacy projects it includes in a Results Narrative?**

* Choose [technical assistance service requests](#Technical_Assistance), [cases](#Case) or projects that are representative of the range and breadth of their work and achievements;
* Choose examples that will demonstrate how the P&A is making progress on the goal and its related priorities.
* If the P&A is facing barriers, choose examples that explain those challenges assisting the reviewer in understanding the degree of progress made at the close of the report period.
* Choose at least one example for each of the P&A’s priorities;
* Complete enough Results Narrative grids to demonstrate the value of your P&A program. Admittedly, this is subjective but it is important to keep in mind whether what is reported in the PPR documents that the P&A ‘earned’ the amount of money spent for the report period;
* At a minimum choose enough cases or projects to demonstrate the required [collaboration](#Collaboration) with the DD Network, Long Term Care Ombudsman, and Client Assistance Program if it is not part of the P&A. If your collaborations with these entities do not involve the pursuit of one or more of the End Outcomes, be sure to discuss this year’s activities with these collaborators in the appropriate Other Qualitative Narrative sections.
* At a minimum choose one case or project where underserved/unserved/minorities were targeted to better benefit from P&A intervention.
* At a minimum choose enough cases or projects to have at least one example for every performance measure used to report outcomes (See [Performance Measurement Tables](#Performance_Measure_Menu) in the guidelines for Part III below). For example, if somewhere in your report includes data in five of the End Outcome performance measurements in the report; three from the System Litigation table and two from the Abuse and Neglect Investigations table, then at least one example of each must be provided in a Results Narrative grid. If one individual technical assistance service request, case, or project described in a Results Narrative provides an example of all the performance measurements used, the minimum requirement would be met. But it is more likely to take a combination of several technical assistance service requests, cases or projects to complete this requirement.

1. Other people include family members, direct support providers/workers, personal care attendants, and other support providers. [↑](#footnote-ref-2)