Workgroup 4 Recommendation: Mistreatment, Abuse and Neglect

Workgroup Focus Area: Individuals and their families experience consistent, transparent, accountable, and data-driven systems that focus on outcomes.

Workgroup Priority #3: Strengthen DDS, regional center, vendor, and provider accountability for achieving equitable and person-centered outcomes.

Priority #3 Plain language version: Make sure DDS, regional centers, vendors are responsible. They need to provide the services they are supposed to. They need to give fair and person-centered results.

Step 1: Define a Universal Goal for the Priority (Where we want to be)

People get the services and supports they need, when they need them, so they can lead the lives they want.

The overarching goal is to make sure that vendors, individuals and regional centers and other organizations in the system are accountable for mistreatment, abuse, and neglect toward people with IDD.

- Prevent harm to those served by the system.
- Make it clear how problems are reported, investigated, and fixed.
- Give people options to report problems and make them feel confident to do so.
- Strengthen the DDS Office of the Ombudsperson to handle problems better.
- Make sure consequences exist for bad actors and are enforced.
- Consider how to include research and input from stakeholders like The Natalie Project (The Natalie Project). Their specialization is sexual abuse.
- The Medicaid Access Rule: States must set up and maintain an electronic incident management system using a common definition of what is a "critical incident." They must investigate, address and report on outcomes of the incidents, with a requirement to report the results of an incident management system assessment every two years. States have 5 years to put electronic incident manager systems and 3 years to do the other incident management provisions.

Step 2: Develop a Problem Statement for the Priority (Where we are now)

Systemic Failures Leading to Mistreatment, Abuse and Neglect
The regional center is supposed to help and support people with disabilities, but problems in the system can lead to mistreatment, neglect, and abuse. These failures can seriously harm the people they serve, while the regional centers and their service providers often face little or no consequences. Here are real-life examples showing how these issues affect people's lives:

Plain language: The system is supposed to help people, but mistakes and lack of accountability often lead to harm. People face life-changing issues while the system rarely holds anyone responsible.

Examples from Lived Experience:
Example #1: The regional center cancelled an individual's Representative Payee without making sure they had another Representative Payee. For 2 months, the individual could not pay rent or afford food. The decision to change their Payee and Financial Management Service without making sure there was something in place had a huge impact on the individual's life. The individual had to borrow money to pay their mortgage, but their rent and electricity is still not paid. Fortunately, the place they live at is willing to work with them, but many people would face immediate eviction or utility shutoffs. This lack of planning and accountability put the individual at great risk. (Note: Payee manages your personal funds from Social Security whether its SSI or Social Security. Regional center pays your representational payee in both traditional services and Self Determination Program).

Example #2: IHSS worker knew an individual's ATM code, stole $500 from the individual's account, and then lied about it. When the individual reported the theft to the blank, the bank blocked the individual's account and returned the money. The individual reported this behavior to IHHS. The IHSS worker never faced any consequences. She is still in the IHSS system – maybe still doing her thievery.

Failure in Accountability
The system is supposed to keep people with disabilities safe, but it often fails to listen or act when they report abuse or neglect. This leaves people unprotected while those who harm them face no consequences. Here is an example of how this hurts people:

Example #3: In my personal life several types of abuse, by individual abusers. When I do report the abuse, the authorities do not believe me, they think I am lying because I am a person with a disability. They system should believe the person with a disability until proven otherwise. Also, when we do report, we do not get reasonable

accommodations to report abuse, neglect, or mistreatment. Perpetrators rarely have to face consequences for their actions.

Problems Statements:

1. No real consequences for when things go wrong.
2. People don't know how to report problems or what happens after they do.
3. People in authority do not believe people with disabilities have been abused, neglected, or mistreated.
4. DDS and the Ombudsman don't have the resources to enforce rules effectively.
5. Vulnerable groups like non-English speakers, those with complex needs and abuse victims are left behind.
6. Fear of intimidation and retaliation from the abuser for reporting.

<u>Absence of Consequences for Systemic Failures (or enforcement of consequences)</u>
There are lots of consequences for clients that are life-threatening or life-altering, but there are no consequences for the regional centers or for their vendors.

<u>Additional Problem Statements</u>

7. The current system lacks comprehensive accountability mechanisms resulting in inconsistent delivery of equitable and person-centered services. No real consequences when things go wrong.
8. People don't know how to report problems or what happens after they do.
9. There is limited enforcement of consequences for misconduct, contributing to a lack of trust in the system(s).
10. While DDS and the Ombudsperson provides support, it lacks sufficient authority and resources to effectively enforce accountability measures.
11. Without systemic improvements, the developmental services framework risks failing to meet its goals of safety, equity, and person-centered care for all individuals it serves.

Step 3: Identify the Root Causes of the Problem

The root causes of the problems include the following:

- There are no timelines for the Person-Centered Plan and Spending Plan for the Self Determination Program.
- There is no follow-up or soft pass off with change of Regional Center Service Coordinator. Previous Service Coordinator did not communicate or complete promised tasks leaving critical matters not completed and new plan not in place.
- Life threatening, life-alternating and financially critical events not prioritized. "Individuals feel they are left standing at a precipice."
- There is no way to find out if a day program has a history of abuse. Not taking steps to make sure this does not happen to the next person.
- There is no statewide tracking of Special Incident Reports (to identify trends or habitual offenders).
- Law enforcement training on Adult Protective services, ensure offender prosecution is to the fullest extent of the law.
- State to consider an abuser registry. The Massachusetts DPPC has this. Once listed you can not be unlisted. It Is well known. No consequences for the individual – no-one knows about you, and you can repeat your abuse.
- Mandated Reporter Trainings.
- Limited provider expertise and resources exacerbate challenges in meeting people's needs.
- One of the most important sections of the Special Incident Report Form is the last section which is intended to plan how to prevent the incident from happening again. There is no tracking of how this plan is implemented and followed up on.

Who is being left behind:

The system currently leaves behind many groups of individuals and families, including the following:

1. Underserved Populations: Latino, Black, Indigenous, and other communities of color face persistent disparities in access to equitable services, cultural competency, and language-appropriate resources.

2. Non-English speakers encounter barriers due to inadequate availability of translated materials and bilingual staff.

3. Individuals with Complex Needs: Those with severe disabilities, non-speaking or who use communication devices, mental health conditions, or medical complexities often struggle to receive person-centered services tailored to their unique circumstances.

4. Victims of Abuse or Neglect: Individuals who experience abuse or neglect often lack safe, accessible reporting mechanisms and comprehensive follow-up support. Fear of retaliation, inadequate investigations, or insufficient consequences for bad actors perpetuate cycles of harm.

5. Youth Aging Out of Services: Adolescents transitioning into adulthood face significant gaps in services and supports, resulting in disruptions to care and a lack of person-centered planning for independent living.

6. Elderly people are highly targeted by perpetrators in all types of abuse. People with intersectional identities- age (senior citizen), person with a disability, race, and gender.

Step 4: Recommendations to Achieve the Goal

Recommendations for a Safer and More Accountable System

Overall recommendation is to adopt The Massachusetts DPPC model. (MA Disabled Persons Protection Commission)

1. Prevent Harm to Individuals Served by the System

- Safeguards and Risk Assessment: Establish proactive risk assessment protocols to identify and address potential dangers early.

- Provider Training: Standardize training on harm prevention, trauma-informed care, mandatory reporting, and ethical practices. Enforce strict consequences for failing to report incidents on time. Make sure that trainings do not incentive or encourage inappropriate referrals and separation of families. Ensure that mandated reporters have both access to and training on services and supports that are culturally aligned with and responsive to the needs and preferences of people served and their families.

- Training for Persons Served and Their Families: Provide training and resources to individuals and families on recognizing harm, understanding their rights, and navigating the reporting process. Expand availability of services and supports that teach people served and their families about healthy and safe relationships and how to recognize sexual abuse and coercion.

- Advocacy Support: Establish independent advocates or peer-support networks to assist with reporting and follow-up. DPPC has a training curriculum for peer support networks.
  - Peer training by self-advocates for all kinds of audiences – self advocates professionals, law enforcement, DA offices, APS social workers and DDS.
  - Peer to Peer training: training by self-advocates to other self-advocates who have lived experience in abuse to help others. They can help them on the path of healing.

- Harm Prevention Approaches. Develop strategies to address systemic problems before harm occurs.

2. Prioritize Critical Needs with Checklists and Timelines

- Checklist for Urgent Help: Create a checklist for prioritizing urgent cases, such as life-threatening medical needs, danger of housing loss, homelessness, or critical safety concerns. These issues must be addressed immediately, not delayed until the next IPP meeting. Implement a triage system to manage and prioritize high-risk cases effectively.

- Timelines for Action: Establish clear timelines for service approvals, plan renewals, time for appealing, and urgent requests. Ensure timelines are communicated to both clients and Service Coordinators.

- Enforce Consequences: Introduce penalties for missed deadlines that impact service delivery, holding Regional Centers accountable, not just persons served.

3. Increase Transparency in Reporting and Investigations

- Centralized Reporting System: Create a portal to track incidents, investigations, and outcomes in real-time. Make data about incidents and how they are handled available to the public without sharing personal details. This helps people see what is being done to fix problems and holds regional centers, providers, and others responsible for their actions. Corrective Action Plans should be available to the public.

- Regular Reporting: Require DDS, Regional Centers, and providers to report incidents and resolutions consistently.

- Accessible Reporting Mechanisms: Develop easy-to-use systems for reporting concerns, including digital platforms and multilingual hotlines.

- Public Registry: Create a public registry to prevent people from re-abusing. Model after the sexual abuse registry.

4. Strengthen the DDS Office of the Ombudsperson

- Clear Role and Resources: Define the Ombudsperson's role and provide the necessary resources and authority for effective investigations and enforcement.

- Best Practices: Adopt successful strategies from other departments' Ombudsperson offices to enhance DDS operations.

- Direct Communication: Create a channel for the Ombudsperson to escalate systemic issues to leadership or external oversight bodies.

5. Create and Enforce Consequences for Misconduct

- Standardized Guidelines: Develop uniform guidelines for addressing misconduct by providers, vendors, and staff, including timely and proportionate penalties like fines, contract termination, or license revocation.

- Public Accountability: Publicize actions taken against bad actors to demonstrate transparency and deter future violations. Ensure that settlement agreements do not prevent the public disclosure of factual information about sexual offenses, as required by California Code of Civil Procedure section 1001. There is a need to work with DA office to properly prosecute the organizations and individuals who do abuse, mistreatment, and neglect against people with IDD. (There is an excellent model in Massachusetts on accountability - MA Disabled Persons Protection Commission). Work in many communities and with law enforcement officers to prosecute these villains. The also have a statewide abuse reporting line that goes into the DPPC (Disabled Persons Protection Commission).