

To: DDS

From: Karen Mulvany, family advocate

Re: Comments on proposed revisions to Special Incident Reporting regulations

Date: April 22, 2025

Thank you for taking public comment on the proposed revisions to Special Incident Reporting regulations.

1. Per section 54327(d)(2), "isolation" is considered reasonably suspected abuse or exploitation, and on p. 3, section 54327(a)(16) "isolation" is defined as:  
"Isolation" means:
  - A. Intentionally preventing an individual served from receiving personal mail or telephone calls;
  - B. Telling a caller or prospective visitor that an individual served is not present, or does not wish to talk with the caller, or does not wish to meet with the visitor where the statement is false, is contrary to the express wishes of the individual served, whether the individual is competent or not, and is made for the purpose of preventing the individual from having contact with family, friends, or concerned persons; or
  - C. False imprisonment.
- My comments:
  - i. Consider whether the "and" in boldface above in subsection B should instead be "or". I truly appreciate the intent of this definition, however, please consider whether family friends and concerned persons, in order to regain access to an individual, would be effectively stymied unless they were able to provide proof of the vendor's purpose in preventing the individual from having contact with them. A vendor's purpose is exceedingly difficult to prove or even substantiate because all of the evidence is under the vendor's control. Instead, shouldn't it be the vendor who is required to provide documented and verifiable evidence that the individual wishes to refuse a visit with family, friends and concerned persons? And if the individual can't effectively and reliably communicate, shouldn't the presumption be that conservators, guardians, parents of minor individuals and authorized representatives should be granted reasonable access to the individual?
  - ii. Subsection (B) above does not but needs to provide family, friends and concerned persons with an actual means of obtaining evidence that the individual is or is not refusing a visit to see them, or a vendor could refuse them access indefinitely based solely upon the vendor's own assertions. As the former chair of the Sacramento SCDD RAC, I heard many stories of such incidents, and continue to hear them to this day. Just last year as I was interviewing a professional conservator as part of a long term planning process, I was asked how to deal with a vendor who was refusing the conservator access to a conservatee, which had been going on for months. For individuals who are under limited conservatorship, it should be made clear when visit decisionmaking is a conservator's responsibility while also noting that conservators are already required to honor the conservatee's wishes provided those do not conflict with health and safety considerations or other factors important to the individual's well being. For individuals

who are functionally nonverbal or inaccurate in their communications, or merely susceptible to manipulation, it is worryingly easy for a vendor to simply claim that the individual didn't want to see family, friends or a concerned third party. There's no means for family, friends or concerned persons to prove otherwise when access to the individual has been preemptively restricted by a vendor or RC, and vendors and RCs are the sole entities empowered with access to assess the "express wishes" of the individual.

- iii. As a general conservator myself, I have encountered vendor efforts to restrict my access to my conservatee, not because the conservatee didn't want to see me, but because the vendor or their support staff believed it was their right to control my access to the conservatee. Support staff and vendors should not be effectively empowered to escape oversight, when that oversight is a legal responsibility of a court-appointed conservator, especially for our most vulnerable individuals. Abuse and neglect is unfortunately too common in this population. Consider whether an individual who has been assessed to lack the capacity to appropriately judge danger to themselves or is functionally nonverbal is especially vulnerable and therefore should be entitled to the oversight of authorized representatives of the individual served, including without fail, conservators.
2. Section 54327(a) should include an additional definition for "authorized representative of the individual served", to include:
    - a. For adult individuals served:
      - i. Any conservator legally empowered to make decisions on behalf of the individual served, provided those decisions do not exceed any designated limits to the conservator's decision making powers;
      - ii. Any supported decision maker authorized by the individual served to assist them provided their decisions do not exceed any designated limits to their decision making powers;
      - iii. Any person with written power of attorney pertaining to the decision making area, and
      - iv. Any person designated by the individual served or their conservator as an authorized representative for general purposes or a specific decision making area.
    - b. For minor individuals served:
      - i. Any parent;
      - ii. Any guardian, and;
      - iii. Any person designated by a parent or guardian as an authorized representative for general purposes or a specific decision making area.
    - c. For all of the above, consider whether such persons should be documented in the individual's IPP along with any limits to the decision-making powers of such persons.
  3. In section 54327 (c)(2)(E), please revise this to read "sexual assault, rape, or an attempt to commit sexual assault or rape." Note that the definition section includes separate definitions for sexual assault and rape such that one does not include the other; consequently all should be mandatory reported incidents. Additionally, there should not be an implied requirement for multiple attempts to commit sexual assault or rape to have occurred before reporting is required; one attempt should suffice.

4. In section 54327 (d)(3), all vendors are required to report “reasonably suspected neglect” which includes the “negligent” failure to:
  - A. Provide medical care for physical and mental health needs, including failing to administer required health care interventions;
  - C. “Protect from health and safety hazards, including failing to prevent two or more falls in a thirty (30) day period;”
  - a. With respect to subsection (A):
    - i. Certain vendors, notably respite providers, are prohibited from providing medication, even when ordered by a doctor and required by the individual, even under emergency conditions, and even though Health and Safety section 1799.103 conflicts with these prohibitions. It is not reasonable to impose this requirement on providers who are prohibited from assisting even in a medical emergency.
    - ii. Nasally delivered emergency medication is now available for prolonged seizures and anaphylactic shock, using the same simple delivery device that is dispensed at no charge to laypersons for the purpose of assisting with opioid overdoses. My hope is that DDS will address current medication assistance prohibitions that endanger the health and safety of individuals served, possibly by setting up a framework enabling employees of vendors to volunteer to assist with needed medication in a medical emergency. See <https://www.dgs.ca.gov/OAH/Case-Types/General-Jurisdiction/Resources/-/media/Divisions/OAH/General-Jurisdiction/DDS-Decisions/2016050867084Acc.pdf>
  - b. With respect to subsection (C):
    - i. For active ambulatory individuals with CP, balance disorders, and/or seizures, less than 2 falls a month can be a highly unrealistic goal —unless the individual is restrained 24x7, which is typically far too restrictive a solution. What constitutes “negligent failure” should be in the definitions section and should be confined to what should reasonably have been foreseen, such as tripping while traversing the edge of a sidewalk, rather than a sudden drop brought on by an individual’s unpredictable medical condition in a familiar home environment which resulted in no injury more serious than a minor bruise.
    - ii. As a family advocate, my chief concern is that providers will simply decline clients if they are held to an unrealistic support standard, leaving individuals bereft of services.
5. In section 54327 (d)(5), all vendors are required to report hospitalizations arising from multiple scenarios.
  - a. Please consider adding allergic reactions to the list of scenarios, including anaphylactic shock from insect stings, foods, medications, or other sources.
6. With respect to section 54327.1. Requirements for Special Incident Reporting by Regional Centers:
  - a. For subsection (c)(12), consider adding “and vendor” to the end of “Relationship of the alleged perpetrator to the ~~consumer~~individual served;”
    - i. It is vitally important for regional centers to understand any relationship between a vendor (or their employees) and an alleged perpetrator.

- b. For subsection (c)(16), consider adding the DDS Office of the Ombudsman (<https://www.dds.ca.gov/initiatives/office-of-the-ombudsperson/>) and the DRC Office of Client Rights Advocacy.