

**Testimony of Stephen H. Surovic, Executive Director, The Arc of Pennsylvania
Before the Mental Health Subcommittee, Health & Human Services Committee,
PA House of Representatives, Harrisburg, Pennsylvania**

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Thank you Chairman Wheatley for inviting The Arc of Pennsylvania to provide testimony on the important topic of health and safety oversight and incident management within in the community mental retardation services system.

My name is Steve Surovic and I am the Executive Director of The Arc of Pennsylvania, a statewide non-profit organization that provides advocacy and resources for citizens with intellectual and developmental disabilities and their families. The Arc of PA was established in 1949 and is affiliated with 36 local chapters covering 52 counties across Pennsylvania. It is also affiliated with The Arc of the United States based in Washington, D.C. We are a grassroots, member-driven organization with over 9,300 members in Pennsylvania. All of our local chapters provide advocacy for individuals with intellectual and developmental disabilities and their families, and a number of our chapters provide services as well.

My testimony today is intended to raise a number of issues and pose several questions about the oversight of Pennsylvania's community MR system. They are in no particular order of importance, but they are all issues that warrant further consideration by state officials.

Issue #1 – The system is confusing. The system of protections and quality improvement for community MR programs is extremely confusing to individuals receiving services, their families, and their advocates. I know this hearing is intended to focus on community group homes, but I believe the committee ought to be aware of how group homes fit into the overall service system, and how other key components of the system are regulated. For example, Pennsylvania's state-run centers for people with MR are not licensed. No license, no inspections by outside independent parties, no nothing. In addition, private Intermediate Care Facilities for People with Mental Retardation (ICFs-MR) are indeed licensed, but it is very confusing because both the Department of Health and Department of Public Welfare share some responsibility for

regulating them - one state agency does the inspections and the other state agency issues and renews the license. With respect to community-based programs such as group homes, the licensing function is the sole responsibility of DPW-ODP – but it is very confusing to individuals and families. It is not clear or well publicized to families or advocates where they can go or call when they have a complaint or health and safety concern about a loved one. The Arc of PA has been told that if a family has a concern to report, they are supposed to contact the provider, or the county MH/MR office, or call ODP’s toll-free number in Harrisburg. Unfortunately, most families are not aware of who to contact. Further, contacting the provider is not always the best approach – especially if it’s the provider that is causing the problem for which the family has concerns. The county MH/MR office is also problematic because they are NOT responsible for enforcing licensing regulations. They are not the licensing body. Counties do not possess the statutory authority to license programs. Only the state holds such authority and responsibility. Finally, the toll-free number in Harrisburg is not staffed 24/7. So, if a family sees something after business hours or on the weekend and they call the 800 number, they are likely to get a recording.

Issue #2. There is no single office within DPW-ODP responsible for licensing. Adding to the confusion, and perhaps pointing to another more fundamental underlying concern, is that if one looks at the DPW-ODP organizational chart, there appears to be no distinct office, bureau or division within DPW-ODP that is dedicated solely to the licensing responsibility. Licensing is the most fundamental and primary means by which state officials can ensure the health and safety of individuals with intellectual disabilities receiving services, yet the licensing function and the staff dedicated to it are all over the place. It is my understanding that licensing staff in Harrisburg are 4 levels down from the Deputy Secretary, under risk management, program management, and a bureau director. At the regional office level, there are licensing supervisors in place, but they each report to the regional program manager rather than a director of licensing. There is no direct reporting relationship to a licensing director at headquarters. The lack of a distinct and clearly defined office, division or bureau within ODP for licensing not only confuses individuals, families and advocates in terms of where to go for action when a loved one is mistreated, but it may be contributing to confusion within state government itself causing a “blurring of lines” within ODP relative to its other functions, such as program administration and quality improvement.

Issue #3 – Health & safety vs. quality. While licensing, health & safety, and protection from abuse and neglect are core responsibilities of state government, quality improvement is something different and more subjective. The Arc of PA believes that the best determiner of quality is the individual receiving services themselves. The state’s IM4Q program (Independent Monitoring For Quality) is an excellent program in Pennsylvania whereby individuals receiving services are randomly selected and interviewed with a series of survey questions to determine if they are happy and living the life they want. Public policy makers must understand the difference, and strike the appropriate balance between, protecting people and enabling them to pursue happiness and live an “everyday life.”

Issue #4 – “Incident management” needs clarity and improvement. It is not clear to many within the system where “incident management” fits in. Is it to identify and report non-compliance with regulations so the incidents can be investigated and then sanctions applied to the parties involved, or is it intended to be an open and transparent way for parties in the system to report problems they encounter or imperfections they see during day-to-day service provision so the reports can be analyzed and used to develop systemic improvements from which all providers and caregivers can benefit? If the former, then the state needs to take greater control of the system and take responsibility for investigating the serious problems uncovered through the incident management reporting system. If it’s the latter, however, then the purpose of incident management needs to be articulated more clearly to everyone involved and a number of improvements made to the system.

One question that has been raised in media reports is whether providers ought to be doing investigations of themselves in response to incidents. To me, the answer to that question depends on where incident management fits in. What is it for? If it’s intended to be primarily a health and safety protection function, then providers should NOT be investigating themselves. However, if it intended to be a systems improvement function that supplements the primary health and safety protection done through licensing, then there is value in having providers conduct self-investigations.

Regardless of where incident management fits in, several improvements can be made to improve its effectiveness. In recent months, The Arc of PA has asked a number of questions to individuals within state government and those outside state government who interact with the incident management system to attempt to identify potential problems and weaknesses. Allow me to articulate a number of those issues we found. We stress that we are not painting everyone with the same brush. We know there are some within the system who take incident management very seriously – direct care workers, provider managers, county staff, and state officials at ODP. However, many do not, and because there is such inconsistency across the system, we believe these issues must be examined by public policy makers in hopes that the system can be improved and function as it was intended. The issues are as follows:

- a. Not all incidents are being reported. There may be a need for training for those in the system so they can properly identify the kinds of things that should be reported, and training for “point persons” so they can make better judgment calls as to whether something ought to be reported.
- b. The quality of incident reports should be improved. They are often incomplete. It begs the question whether county MH/MR offices consider incident reporting important because, if they did, would providers get away with submitting such reports?
- c. Many county MH/MR offices do not respond to incident reports in a timely or adequate manner.
- d. The incident report summaries prepared by certified investigators are often incomplete and poorly done.
- e. It’s not clear state ODP licensing officials are in the loop of incident reports, which is a problem if an incident report reveals abuse or neglect and/or a violation of health and safety regulations. ODP apparently have “risk managers” involved, but what is their role? Is it appropriate for risk managers, not licensing staff, to become involved in a matter that is really a health and safety situation?

- f. There appears to be little or no analysis being done of aggregate incident data. For example, if a particular provider is reporting no incidents, isn't that a red flag? If they're reporting a lot of incidents, isn't that a red flag? Data should also be analyzed to identify and develop system improvements so they can be communicated to the larger provider community.
- g. Supports coordinators should be doing more with incident reports. For example, if incidents are being reported involving someone on their caseload, perhaps the individual's Individualized Supports Plan (ISP) needs to be revised – perhaps a new service added or something changed to address a root cause of the individual's behavior.
- h. It seems incident reports are only seen by parties “in” the system (i.e., providers, county officials, regional ODP point persons, etc.). Parties outside the system should be able to see reports (with confidential information redacted) so that a fresh and independent set of eyes can examine the data.

Issue #5 – While the current system needs to be improved, public policy makers must keep in mind that new mandates, requirements, and regulations add to the cost of providing services. Complying with rules, regulations, policies, and new statutes require time and effort to carry out. New responsibilities placed on direct support professionals divert attention from service provision and precious resources must be dedicated to regulation compliance. The community MR system is 100% funded by the public sector. Increases in rates to providers have been few and far between. The non-profit sector providers and their staff are already under-funded and under-paid compared to their public sector counterparts. The Arc of PA always supports new health and safety requirements if they are necessary, but public policy makers MUST provide adequate financial resources to providers to comply with the new regulations.

Issue #6 – My testimony has focused entirely on systems that are in place for people being served by the community MR system. I'd like to close by reminding the committee that Pennsylvania is one of five states that does not have an Adult Protective Services statute. Such a law would be similar to other protective services laws in Pennsylvania, such as the Older Adult Protective Services Law and the Child Protective Services Law. However, those laws protect

children until they're 18 years old, and older citizens 60 years of age and older, but vulnerable citizens ages 18-59 have no such protective services law. Such a law would be foundational to all other systems of protection and quality improvement. Any vulnerable citizen, whether in a licensed group home or in a private residence, would be protected under such a statute. Friends, neighbors and family members would be able to report suspected cases of abuse and neglect, and protective services officials would be able to investigate the report. If such a law was passed, some pressure might be taken off the other systems in place, such as licensing and incident management.

In closing, I want to thank the committee for holding this hearing. It is a very important topic. I will do my best to answer any questions you may have. Thank you.