

# LEGISLATIVE RECOMMENDATIONS

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Additional Safeguards from Individuals' Rights Violations, Abuse, Neglect and Exploitation of People with Developmental Disabilities

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#### Introduction

This report is prepared for interested legislators on behalf of MACDDS, The Missouri Association of County Developmental Disabilities Services, a leader in local and state initiatives for people with developmental disabilities. MACDDS is comprised of (63) county boards and (15) related non-profit organizations. This report advocates for specific statutory changes to provide additional safeguards from individuals' rights violations and from abuse, neglect and exploitation of people with developmental disabilities.

Since 2006, significant changes have occurred in Missouri concerning the system that monitors the provision of licensed and certified protective oversight services in residential and day programs for persons with developmental disabilities. These changes include: the Department of Mental Health, Developmental Disabilities Division, transferring case management to local providers. As a result, more than 26,000 eligible persons who previously received case management and service monitoring from State Regional Offices now receive local case management, typically the County Developmental Disabilities Resource Boards created pursuant to Chapter 205.968 RSMo (SB40 Boards). Thus, the Division's relationship to providers of service and persons served has been altered. The positive benefits include: higher family satisfaction, better access, more persons served, greater staff productivity, lower staff turnover, and greater continuity of involvement with caseloads.



Source: 2017 MACDDS Annual Report

While there have been many positive changes in the system, very few changes have occurred in statute or regulation with respect to shifting the role of case management and service monitoring from the State to local government., This shift has resulted in problems with communication and decision making that need to be addressed. MACDDS recommends additional safeguards through statutory reforms designed to ensure better transparency, communication and accountability to protect clients' rights.

#### Safeguarding People Who are Vulnerable

Most studies of abuse of children and adults with intellectual and developmental disabilities (I/DD) find that they are abused more frequently than children and adults without disabilities. The most recent crime data from the

Bureau of Justice Statistics finds that individuals with multiple disabilities fare the worst of any, that is, are victimized more than any other category of individuals. This information alone should be a call to action...immediate action, to reduce the risk of abuse, to intervene quickly when abuse is discovered, to provide treatment and support to the victims/survivors, to arrest and prosecute the perpetrators, and take all known action to reduce the risk of additional victimization. A national survey conducted in 2012 found that over 70% of respondents with disabilities said they had been abuse victims, and 90% of them said it had happened many times. Only about half of the victims reported the abuse and half of those said nothing was done in response to their report. Over half had suffered physical abuse and 42% had been sexually abused. A meta-analysis of studies of child abuse victims with disabilities found that they are abused more than those without disabilities, but it was not clear by how much. With the high rates of abuse, "more" for persons with disabilities is not acceptable.

### MACDDS Legislative Recommendations for Five Additional Safeguards

Recent media attention regarding violation of individuals' rights and the abuse, neglect, and exploitation of individuals with developmental disabilities has called into question whether Missouri has adequate safeguards for people with developmental disabilities. (Sections 630.110, 630.115, and 198.088 RSMo address various rights of individuals.) MACDDS is proposing five specific recommendations for statutory changes to better safeguard individuals with developmental disabilities.

• Recommendation #1: MACDDS recommends Section 630.115 RSMo, which provides the client with "the right to an impartial administrative review of alleged violations", be amended to identify responsibility for conducting the review, the timeframe within which it is to be conducted, and responsibility to share information with the service monitoring entity.

Background: Section 630.115 RSMo setting forth the administrative review process for violation of clients' rights lacks specificity and accountability as to process and responsibility and lacks the force of law or regulation. These inadequacies lead to administrative indecision and confusion in response to reports of individual violations. The statute also limits communication and information sharing between a county board and the Division of Developmental Disabilities when there are alleged violations of clients' rights or reports of suspected abuse, neglect, or exploitation involving a client for whom the state and county agencies are purchasing services and the county board is performing service monitoring. The Department of Mental Health, as the designated state agency, should clearly be required by statute to investigate, communicate, share and disclose to the county board and local case manager the fact that reports of rights violations or of abuse, neglect of exploitation have been made, and the results of investigative findings and final reports, both substantiated or unsubstantiated.

Most issues identified as potential rights violations are not initially reported as suspected incidents of abuse, neglect or exploitation. Rather, they are considered a violation of "patients' entitlements", set forth in section 630.115 RSMo. This statutory section provides the client with "the right to an impartial administrative review of alleged violations", but the statute fails to identify responsibility for conducting the review, the timeframe within which it is to be conducted, and responsibility to share information with the service monitoring entity.

Conducting an administrative review in response to the filing of a report of alleged violation of rights promotes respect for clients' rights and assists in the identification of potential problems before they become instances of abuse or neglect. Examples of alleged violations include review of an unexplained significant change in the health of an individual, denial of an opportunity to live in a less restrictive setting or to work in the community, lack of

prompt medical attention, failure to make the individual available for face-to-face meetings. The process as it currently exists lacks specificity; there are no required timeframes for investigation; there is no required sharing of findings of fact, conclusions and recommendations; and the requirement of a "neutral decision maker" is not defined. The client, guardian/parent, conservator, and/or public administrator deserves these protections. A better structured review will likely lead to improved care. Clients' rights may be further protected by statutory language clarifying that the right to administrative review does not limit the right of any person to bring appropriate legal action in any court of competent jurisdiction to enforce any legal right or to seek damages. In addition, the department should be required to notify the County Board and local case manager serving the individual whose rights have allegedly been violated of the allegation, the investigation, and findings of fact, conclusions and recommendations to ensure accountability and system improvement. Without statutorily required protections, violations that begin as addressable problems may become actual instances of abuse, neglect or exploitation.

The Division has established a process for the reporting of such issues by directive, without the benefit of the promulgation of a state rule. Without the benefit of a statute or rule, any findings of the department may be disputed by the alleged perpetrator as without legal authority, which may result in an inability to enforce clients' rights.

• Recommendation #2: MACDDS recommends the Department be required in Section 630.167 RSMo to share reports of potential abuse, neglect or exploitation with County Boards.

Background: When reports of potential abuse, neglect or exploitation are made, the department is not required by statute to share the reports with County Boards. MACDDS recommends, amending Chapter 630.167 to change the wording Paragraph 3.(1) from "All such reports may be disclosed by the department . . . to boards appointed pursuant to sections 205.968 to 205.990 that are providing services to the patient, resident or client as necessary to report or have investigated abuse, neglect, or rights violations of patients,, residents or clients . . ." to "All such reports may *shall* be disclosed by the department . . . to boards appointed pursuant to sections 205.968 to 205.990 that are providing services to the patient sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided appointed pursuant to sections 205.968 to 205.990 that are provided a section sections 205.968 to 205.990 that are provided a copy upon request of an unredacted final report, whether or not substantiated, for the purpose of monitoring the provision of services and improving the quality of care. As the statute currently provides, the reports shall remain confidential and are not considered to be public records. This statutory amendment will improve accountability through necessary and appropriate transparency.

## • Recommendation #3: MACDDS recommends Missouri statutes be amended to assign responsibility for investigating retaliation against mandated reporters and establish legal penalties.

Background: Many experienced professionals within the developmental disabilities field cannot recall a circumstance in which an alleged offender has been prosecuted for retaliating against a mandated reporter. This is not to say retaliation is not occurring, but suggests circumstances exist resulting in limited investigations and prosecutions for retaliation against mandated reporters. MACDDS recommends Missouri statutes be amended to assign responsibility for investigating retaliation against mandated reporters and establish legal penalties.

## • Recommendation #4: MACDDS recommends the Missouri statutes be amended to mandate criminal background checks for court appointed guardians.

Background: While some circuit courts do require them, currently the State of Missouri does not require background checks for guardians of individuals with developmental disabilities, an important safeguard against the possibility of abuse, neglect and exploitation. Many other states require background screenings for guardians. MACDDS recommends the Missouri statutes be amended to mandate criminal background checks for court appointed guardians.

• Recommendation #5: Unless the guardian, or an immediate relative is the subject of an investigation, MACDDS recommends, the Missouri statutes be amended to authorize, upon initiation of an investigation, or upon the decision to decline an investigation, the Department of Mental Health, shall provide the guardian, copies of all records related to abuse, neglect and exploitation decisions and investigations for the guardian's ward. Provisions for the confidentiality and protection of reporters should be clarified.

Background: Currently, guardians may not even be aware of alleged reports or active investigations related to providers or other agencies involving their wards. This lack of transparency and accountability is a breeding ground for potential abuse, neglect and exploitation. Unless the guardian, or an immediate relative is the subject of an investigation, MACDDS recommends, the Missouri statutes be amended to authorize, upon initiation of an investigation, or upon the decision to decline an investigation, the Department of Mental Health, shall provide the guardian, copies of all records related to abuse, neglect and exploitation decisions and investigations for the guardian's ward. Provisions for the confidentiality and protection of reporters should be clarified.

### **Additional Resources:**

For additional information on Guardianship Reform see the CV for Thomas Coleman, a Human Rights Attorney who presented September 15, 2017 at the 4<sup>th</sup> Annual Educational Summit of The ARC of Missouri.

Thomas Coleman is a human rights attorney and Legal Director for the Spectrum Institute. His research of the Missouri state system "Disability and Abuse: Administering Trauma Informed Justice in Missouri Guardianship Proceedings" was recently presented at the 4<sup>th</sup> Annual Educational Summit of The ARC of Missouri. Coleman's presentation draws upon his experience in the field of disability and abuse as well as his expertise in the field of disability and guardianship. It identified ways in which persons in charge of or participating in Missouri's guardianship system can reduce the risk of abuse and provide an effective response if and when maltreatment is suspected or reported.

As a result of this research, Thomas Coleman and the Spectrum Institute sent a letter to the Supreme Court of Missouri complaining that the state's guardianship system violated the rights of guardianship respondents and wards under the Americans with Disabilities Act. A copy of that complaint, an essay explaining the duty of the Supreme Court to bring the guardianship system into compliance, the letter sent to the Department of Justice and the Spectrum Institutes website like can be found below.

http://spectruminstitute.org/Missouri/supreme-court-letter-and-attachment.pdf http://spectruminstitute.org/Missouri/supreme-court-ADA-duties.pdf http://spectruminstitute.org/Missouri/rebecca-bond-letter.pdf http://spectruminstitute.org/Missouri For additional information on Incidence and Prevalence, Prevention and Treatment of Abuse and Neglect of persons with Developmental Disabilities see the CV for Dr. Nora Baladarian, a Clinical Psychologist, who presented September 15, 2017, at the 4<sup>th</sup> Annual Educational Summit of The ARC of Missouri.

Dr. Nora Baladerian, is a licensed Clinical Psychologist with the Counseling Center of West Los Angeles and Disability and Abuse Project of the Spectrum Institute. She specializes in trauma or abuse related issues, victim assistance, children and adults with disabilities and is a vendor to the Regional Centers for Developmental Disability. Dr. Baladerian is the Project Director for Child/Adult Abuse & Neglect Disability Outreach Project "Can Do" under ARC Riverside, is the Director of the Disability and Abuse Project since 1991 and is President of the Spectrum Institute. With an expertise in serving crime victims with disabilities and people charged with victimless sex crimes, she has successfully rallied victim/witness organization leaders, crime victims' rights advocates, social service professionals, forensic psychologists, law enforcement, attorneys, members of the judiciary, and others to take up the cause of ensuring that the needs of society's most vulnerable are not overlooked or otherwise forgotten. http://www.norabaladerian.com/

http://www.disabilityandabuse.org/

http://disability-abuse.com/about-spectrum.pdf