

November 1, 2019

The Honorable Douglas A. Ducey
Governor of Arizona
1700 W. Washington
Phoenix, Arizona 85007

Dear Governor Ducey:

The Abuse & Neglect Prevention Task Force, convened in response to Executive Order 2019-03, extends its appreciation for the leadership and guidance you and your staff have provided in ensuring the health and safety of Arizona's most vulnerable citizens.

We acknowledge the significant responsibility placed on the Task Force to examine a broad range of concerns and opportunities, aimed at enhancing the prevention of abuse and neglect. The Task Force and workgroups met monthly from March through September 2019. We carried out our charge through a facilitated consensus-building process that included in-depth discussions, research, and a review of best practices.

I want to thank each of the Task Force members for lending invaluable insight and subject matter expertise in the creation of the recommendations contained in this report. I also want to express my gratitude to The NARBHA Institute and Vitalyst Health Foundation for their generous support of this endeavor.

Per Executive Order 2019-03, we respectfully submit this report for your review and consideration.

Sincerely,



Jami Snyder
Director



**Report of the Abuse & Neglect Prevention Task Force
To Governor Douglas A. Ducey**

November 1, 2019

Overview of the Report

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Executive Summary

Governor Douglas A. Ducey issued Arizona Executive Order 2019-03 *Relating to Enhanced Protections for Individuals with Disabilities* on February 6, 2019. The Executive Order called for the Arizona Health Care Cost Containment System (AHCCCS), the Arizona Department of Health Services (ADHS), and the Department of Economic Security (DES) to convene a working group to make recommendations that will further protect and improve care for individuals with disabilities. The Abuse & Neglect Prevention Task Force was appointed to carry out this charge. The Task Force commends the Governor for his leadership and direction on improving safeguards for our most vulnerable citizens.

Members of the Task Force, as representatives of the State and its citizens, committed to a careful examination of the factors and conditions that put vulnerable individuals at risk for abuse, neglect, and exploitation. In confronting these challenges, the Task Force identified needed reforms, practices, critical resources, policies, and commitments that must be in place in order to improve and sustain safety and security for vulnerable individuals. The Task Force called for a system-wide trauma-informed approach to policy and strategy development.

The Task Force developed 30 recommendations that are detailed, with timelines, in the body of the report. Themes from these recommendations include:

Statewide Public Awareness Campaign

Arizona should commit to creating a statewide culture of abuse, neglect, and exploitation prevention and should educate the broader public of that commitment through a public awareness campaign.

Prevention and Accountability

All state agencies, in collaboration with private vendors and stakeholders, should develop, disclose, implement, and monitor policies and practices aimed at preventing abuse, neglect, and exploitation, reporting incidents, conducting investigations, and ensuring incident stabilization and recovery.

Multi-Agency Coordination

AHCCCS, DES, ADHS and other critical system partners should employ a coordinated, multidisciplinary team approach in preventing and addressing incidents of abuse and neglect.

Signage

Signage on how to report abuse, neglect, and exploitation should be prominently posted in all settings in which vulnerable individuals reside and/or receive services.

Training for Vulnerable Individuals and Families

State agencies, in partnership with community-based organizations, should offer evidence-based training on abuse, neglect, and exploitation prevention, reporting, and recovery to vulnerable individuals and their families.

Identification, Tracking, and Analysis of Incidents

AHCCCS and DES should continue to explore improvements in tracking and analyzing incidents of alleged abuse and neglect, including mechanisms for making data readily available to the public.

Workforce Development

AHCCCS, in partnership with its contracted managed care organizations (MCOs), providers, industry groups, and regulatory agencies, should develop a comprehensive workforce development strategy which fosters workplaces that uphold the ideals of respect, attentiveness, and active support for all individuals receiving services and providing services within the State Medicaid program.

Adult Protective Services Registry and Training

State-issued contracts should be revised to require Adult Protective Services (APS) Registry checks for prospective direct service employees and training should be offered to investigators and supervisors related to federal and state APS guidelines.

Supportive Resources to Help Manage Caregiver Stress

AHCCCS, in partnership with its contracted MCOs, should provide training and resources to address caregiver stress and burnout.

Public Access to Setting Monitoring Reports

Publicly reported data, including monitoring reports for group homes and adult developmental homes, should be easily accessible on the DES website, to the extent allowed by statute and privacy restrictions.

Review of Confidentiality Requirements

A stakeholder and agency workgroup should be formed to identify potential revisions to statute and agency policies to allow information sharing between parties while maintaining required privacy and confidentiality protections.

Review of Status and Results of Recommendations

A Task Force should be convened by the Governor's Office in late 2020 for the purpose of reviewing progress on these recommendations.

Introduction

The Abuse & Neglect Prevention Task Force was appointed by the Governor's Office in February 2019 to address State of Arizona Executive Order 2019-03 *Relating to Enhanced Protections for Individuals with Disabilities*.

The Task Force was comprised of self-advocates, family members, advocacy organizations, tribal representatives, providers, foundations and public charities, state agency leaders and staff, and members of the Arizona legislature. In addition to appointed members, stakeholders and agency staff participated in five workgroups: Prevention and Safety, Incident Reporting and Investigation, Incident Stabilization and Recovery, Agency Alignment, and Family and Vulnerable Individual Education.

The Task Force and workgroups met monthly in facilitated sessions from March through September 2019. Thirty recommendations were developed through a consensus-building process that included literature searches, research on best practices, and sharing experiences and information.

The facilitator, Task Force, and workgroup members are listed in Appendix 1.

Executive Order

State of Arizona Executive Order 2019-03

Relating to Enhanced Protections for Individuals with Disabilities

WHEREAS all Arizonans deserve to be safe wherever they reside;

WHEREAS vulnerable populations including individuals with disabilities are at increased risk of abuse and exploitation;

WHEREAS the Bureau of Justice Statistics National Crime Victimization Survey found that individuals with disabilities are three times more likely to be victims of violent crime;

WHEREAS individuals with intellectual disabilities are seven times more likely to be sexually assaulted;

WHEREAS these statistics underscore the need for heightened protections for individuals with disabilities living in group homes, intermediate care facilities, and other residential settings.

NOW, THEREFORE, I, Douglas A. Ducey, Governor of the State of Arizona, by virtue of the authority vested in me by the Constitution and laws of the State of Arizona hereby order as follows:

1. The Arizona Health Care Cost Containment System (AHCCCS), the Arizona Department of Health Services (ADHS), and the Department of Economic Security (DES), in conjunction with disability advocates, shall review current protocols and jointly develop training on preventing abuse and neglect, recognizing the signs and symptoms of abuse and neglect, and reporting abuse and neglect for both providers for people with disabilities and for parents and guardians.
2. AHCCCS, ADHS, and DES shall ensure that all state contracts related to the care of individuals with disabilities include a requirement that all staff, contractors, and vendors who have direct interaction with members with disabilities shall annually undergo training in preventing, recognizing, and reporting abuse and neglect.
3. AHCCCS, ADHS, and DES shall ensure that all state contracts for residential, group homes and day programs for individuals with disabilities include a requirement for the prominent posting of signage which includes department approved language on how to report abuse and neglect.
4. AHCCCS, ADHS, and DES shall ensure that all state contracts related to the care of individuals with disabilities include a requirement that a check [be conducted] of the Adult Protective Services Registry before someone is hired.
5. AHCCCS, ADHS, and DES shall convene a working group that includes individuals with disabilities, disability advocacy organizations, providers, and family members. This workgroup shall consider additional steps that can be taken to protect and improve care for individuals with disabilities and shall make recommendations and submit a report to the Governor's office by November 1, 2019.

Abuse & Neglect Prevention Task Force Recommendations

The following recommendations supplement the work already underway by advocates, other stakeholders, and state agencies to address the directives in the Executive Order.

Executive Order Point 1: *The Arizona Health Care Cost Containment System (AHCCCS), the Arizona Department of Health Services (ADHS), and the Department of Economic Security (DES), in conjunction with disability advocates, shall review current protocols and jointly develop training on preventing abuse and neglect, recognizing the signs and symptoms of abuse and neglect, and reporting abuse and neglect for both providers for people with disabilities and for parents and guardians.*

Prevention Strategies, Practices, and Accountability Mechanisms

1. All state agencies, in collaboration with private vendors and stakeholders, should develop, disclose, implement, and monitor policies and practices aimed at preventing abuse, neglect, and exploitation, reporting incidents, conducting investigations, and ensuring incident stabilization and recovery. Policies and practices should be implemented across the range of settings serving vulnerable individuals, including those who are not Arizona Long Term Care System (ALTCS) eligible. By 10/1/2020, AHCCCS and DES contracts should require that all applicable entities develop and implement these policies and practices. (Lead Entity: AHCCCS)
2. All Arizona programs that provide direct services and/or supports to vulnerable individuals should post signage detailing the process for anonymous reporting and whistleblower protections and offer training on the prevention of abuse, neglect, and exploitation. Training for all parties should address retaliation (e.g., harassment or loss of employment) and penalization (e.g., changes to the nature and/or location of services and supports). By 10/1/2020, AHCCCS and DES contracts should require that all applicable entities develop and implement these protocols and practices. (Lead Entity: AHCCCS)

Multi-Agency Coordination

3. By 12/31/2019, DES, AHCCCS, and ADHS should develop and disseminate, to all stakeholders, comprehensive flow charts detailing reporting and investigation processes and oversight mechanisms, including the DES Ombudsman Office and the Independent Oversight Committees (IOCs), for all types of abuse, neglect, and exploitation concerns, incidents, and allegations for all relevant sub-populations. The flow charts should specify the authority and responsibility of each entity and should be updated as needed. (Lead Entity: DES)
4. Stakeholders and state agencies should review current systems in which vulnerable individual maltreatment allegations are reported to government entities to reduce duplication and ensure the most efficient use of resources. Recommendations for any

needed changes should be completed by 3/31/2020 and implemented by 6/30/2020.
(Lead Agency: DES)

5. By 10/1/2020, DES, AHCCCS, ADHS and other critical system partners, such as the Attorney General's Office and the Arizona Corporation Commission, should employ a coordinated, multidisciplinary team approach in responding to incidents of abuse and neglect that includes cross-reporting of allegations to other state agencies and law enforcement partners. (Lead Entity: DES)
6. Beginning no later than 12/31/2019, DES, AHCCCS, ADHS, and the Chairs of the IOCs and/or a representative of the IOCs from the Arizona Department of Administration should hold quarterly meetings to ensure an understanding of each entity's role and responsibility in regard to incident reporting and investigation, and to support a collaborative approach when an incident occurs and multiple entities are involved. (Lead Entity: AHCCCS)
7. The DES/DDD Chief Medical Officer should convene a workgroup of medical directors from AHCCCS and its contracted MCOs to review current standards of care in intermediate care facilities for individuals with intellectual disability (ICF/IIDs), to make recommendations on the prevention of abuse, neglect, and exploitation, and to identify how those recommendations will be implemented. Recommendations generated by the workgroup should be shared with ADHS. Discussions should start no later than 12/31/2019 and the work should be completed by 6/30/2020. (Lead Entity: DES)
8. DES, AHCCCS, and ADHS should convene stakeholders to identify and implement ways to enhance coordination in the sharing of information, eliminate any duplication of functions, and ensure proper community monitoring and oversight as well as the most efficient use of private and public resources to protect all vulnerable people in the state. A report of the identified opportunities and corresponding implementation actions should be provided to stakeholders by 10/1/2020. (Lead Entity: DES)

Review of State Statute Definitions

9. A workgroup including state agencies, legislators, and stakeholders should review definitions of abuse, neglect, and exploitation in state statute for the adult population, and propose any changes needed to ensure clarity. Following any changes to state statute, revisions should be made to contracts and policies and all affected parties should be educated by the contracting agency on the changes made. Contract changes, policy changes, and education should be completed within six months of enactment of any legislative changes. (Lead Entity: DES)

Standards of Board Governance

10. By 10/1/2020, deliverables in all state contracts for services provided to vulnerable individuals should include, in the special terms and conditions, a requirement that nonprofit and for-profit entities show compliance with generally accepted standards of good governance. The contracting agency should provide a checklist with items such as term limits, staggered terms, annual submission of financial statements, conflict of interest disclosure, whistleblower protections, etc. (Lead Entity: AHCCCS)

Training for Vulnerable Individuals and Families

11. State agencies, in partnership with community-based organizations, should provide evidence-based training for vulnerable individuals and their families on abuse, neglect, and exploitation prevention, reporting, and trauma recovery. Programs should be developed and delivered in collaboration with members of targeted populations. (Lead Entity: DES)

Identification, Tracking, and Analysis of Incidents

12. AHCCCS and DES should explore ways to code, track, and analyze all incidents of alleged abuse and neglect. Throughout the system, coding should specify allegations of sexual abuse as distinct from other types of abuse and specify type of disability (within the constraints of privacy restrictions). The agencies should consider available information technology upgrades that facilitate the accessibility of online information to the public, to the extent allowed by privacy restrictions. The agencies should work with the IOCs to determine how to supply data on unsubstantiated incidents to IOC members. This should be completed by 10/1/2020. (Lead Entity: AHCCCS)
13. By 10/1/2020, AHCCCS and DES should find and implement methods to use claims data for the identification of potential abuse and neglect and confirmation that incidents are appropriately reported. (Lead Entity: AHCCCS)

Executive Order Point 2: AHCCCS, ADHS, and DES shall ensure that all state contracts related to the care of individuals with disabilities include a requirement that all staff, contractors, and vendors who have direct interaction with members with disabilities shall annually undergo training in preventing, recognizing, and reporting abuse and neglect.

Workforce Development

14. By 10/1/2020, AHCCCS, in partnership with its contracted MCOs, providers, industry groups, and regulatory agencies, should develop a comprehensive workforce development strategy that fosters workplaces that uphold the ideals of respect, attentiveness, and active engagement for all individuals receiving services and providing services within the State Medicaid program. The strategy should include searchable databases of direct service workers' credentials (e.g., licenses, degrees) and professional development (e.g., online or in-person training courses, certificates) across settings. AHCCCS should require providers to conduct routine testing of staff responses to simulated acts of exploitive, abusive, and neglectful behavior in a manner similar to routine fire and other emergency drills. (Lead Entity: AHCCCS)
15. State agencies, AHCCCS-contracted MCOs, and providers should seek creative, low-cost solutions to safeguard service quality. The State should evaluate current reimbursement to determine whether it is adequate for the State and private companies to be competitive employers. State agencies should maximize workforce development efforts so that providers are able to recruit, adequately train, and retain a qualified direct care workforce in order to provide quality services to vulnerable individuals. (Lead Entity: AHCCCS)

Disclosure and Investigation Training

16. By 6/30/2020, DES should convene stakeholders to develop strategies on trainings related to protection against and disclosure of alleged abuse and neglect, including the Silver Alert program. Everyone to whom a vulnerable individual might disclose an alleged incident should be trained by employers or community-based organizations on what to say — and not to say — to avoid any conversations that might inadvertently interfere with substantiation and/or prosecution. The training should be tiered by role: vulnerable individuals, families/guardians, staff, facility administrators, and APS/law enforcement investigators. A wide range of training mechanisms should be employed, including the public awareness campaign recommended below as well as trainings offered by agencies, providers, and third-party entities. (Lead Entity: DES)
17. All investigators should complete training on the specific special needs of individuals with intellectual and developmental disabilities (I/DD). By 10/1/2020, contracts should require that personnel who investigate alleged incidents in ICF/IIDs, skilled nursing facilities (SNFs), assisted living facilities, and group homes receive training through their employers on how to conduct required investigations. AHCCCS should provide guidance to vendors on the content of such training. (Lead Entity: AHCCCS)

Executive Order Point 3: *AHCCCS, ADHS, and DES shall ensure that all state contracts for residential, group homes and day programs for individuals with disabilities include a requirement for the prominent posting of signage which includes department approved language on how to report abuse and neglect.*

Signage

18. AHCCCS should convene a workgroup, no later than 3/31/20, to determine appropriate signage requirements in all settings in which vulnerable individuals reside and/or receive services. Minimally, by 10/1/2020, AHCCCS and DES contracts should require that signage on how to report abuse, neglect, and exploitation be prominently posted in all such settings. All signage should be appropriate for the setting, culturally appropriate, easy to read and as accessible as possible for clients who do not read, and available in all languages spoken by clients, families/guardians, and staff. Information regarding reporting should be conveyed by contracted providers to all parties through ongoing training and communication mechanisms in addition to signage. (Lead Entity: AHCCCS)

Executive Order Point 4: *AHCCCS, ADHS, and DES shall ensure that all state contracts related to the care of individuals with disabilities include a requirement that a check [be conducted] of the Adult Protective Services Registry before someone is hired.*

Adult Protective Services Registry and Training

19. By 10/1/2020, AHCCCS and DES contracts should be revised to stipulate specific requirements related to APS Registry checks for prospective direct service employees,

including subcontracted direct service employees, paid family members,¹ and volunteers. (Lead Entity: AHCCCS)

20. The APS Registry website should be improved to make it easier for employers to check the Registry before hiring new employees. In the long term, the State should provide funding for a central statewide repository of DCS, APS, and fingerprint information in one data system and on one website. Furthermore, DES should continue to work with stakeholders to determine whether the APS Registry can be enhanced to provide a more comprehensive inventory of caregiver complaints. (Lead Entity: DES)
21. The State should provide funding for a comprehensive APS training program for investigators and supervisors that includes knowledge of federal and state APS guidelines, current research, and best practices to support the APS program. Consideration should be given to the National Adult Protective Services Association (NAPSA) certificate program which is a national best practice. The State should also provide a level of funding for the APS program that takes into account annual growth in the number of reports, fair market wages for investigators, outdated technology across the program, and lack of available service referrals in certain areas of the state. (Lead Entity: DES)

Executive Order Point 5: AHCCCS, ADHS, and DES shall convene a working group that includes individuals with disabilities, disability advocacy organizations, providers, and family members. This workgroup shall consider additional steps that can be taken to protect and improve care for individuals with disabilities and shall make recommendations and submit a report to the Governor's office by November 1, 2019.

Statewide Public Awareness Campaign

22. Arizona should commit to creating a statewide culture of abuse, neglect, and exploitation prevention. A public awareness campaign, developed collaboratively by the Governor's Office, state agencies, and community stakeholders, should include, but not be limited to, these key messages:
 - Arizona values and protects vulnerable individuals.
 - Arizona is committed to recognizing signs and symptoms of abuse, neglect, and exploitation.
 - Arizona encourages all parties to report concerns.

¹ AHCCCS Medical Policy Manual, Section 1240—Home and Community Based Services, 1240-A-Direct Care Services, Section C, describes background check requirements (including an Adult Protective Services Registry screening) effective no later than 10/1/2019 for all Direct Care Workers that are otherwise not statutorily required to obtain a Fingerprint Clearance Card to provide services. As noted in Section C-3-g, agencies may choose to allow exceptions to the background requirements for DCWs providing services to family members only. If the agency allows a DCW to provide services under this exception, the agency shall notify the ALTCS member in writing that the DCW does not meet the background check standards and therefore otherwise would not normally be allowed to provide services, and obtain consent from the ALTCS member to allow the DCW to provide services despite the findings of the background check. Agencies are prohibited from allowing exceptions to the Adult Protective Services screen requirements.

- Arizona supports the provision of information about how to make a report, whistleblower protections, and the process and timeline after a report is made.
- Arizona supports the provision of information about the principles and benefits of trauma-informed care and compassionate care.
- Arizona supports the provision of information about accessing trusted resources for information and support.

(Lead Entity: DES)

23. By 6/30/2020, a workgroup that includes ADHS, DES, AHCCCS, AHCCCS-contracted MCOs, and community organizations should be convened to develop and distribute, upon the request of parents/guardians, educational toolkits to support abuse, neglect, exploitation, and financial exploitation prevention and incident response. The agencies should post proposed toolkit materials on their websites for public comment for a minimum of 30 days, seek input from a representative panel of community stakeholders, and integrate feedback prior to distributing materials. Sample components developed or procured by the workgroups are noted in Appendix 2. (Lead Entity: DES)

Trauma-Informed Approach

24. Arizona should build on previous efforts and implement a system-wide trauma-informed approach, with attention to the special needs of vulnerable individuals and their families, including support when families interact with clinicians, law enforcement, and other professionals. Arizona should support efforts to build and enhance community-based sexual assault services that utilize a trauma-informed approach and address the specific needs of vulnerable adults and their families. Services should be available to all survivors of sexual assault throughout the lifespan and include crisis lines and support groups for survivors of different ages, genders, and backgrounds; sexual assault specific legal and medical advocacy; and counseling by therapists with specialized training in addressing sexual trauma. A description of a trauma-informed model is included in Appendix 3. (Lead Entity: ADHS)

Supportive Resources to Help Manage Caregivers' Stress

25. By 10/1/2020, AHCCCS should require its contracted MCOs to offer training and resources for providers to assist professionals and family caregivers with managing stress and burnout. (Lead Entity: AHCCCS)

Public Access to Monitoring Reports

26. By 10/1/2020, AHCCCS and DES should conduct a review of agency websites and make any necessary changes to facilitate public access to incident data as well as resources related to preventing abuse and neglect and reporting incidents. DES/DDD should post monitoring reports for group homes and adult developmental homes on the agency's website, similar to other licensed healthcare facilities. The agencies should consider the need for statutory or rule changes in order to implement this recommendation. (Lead Entity: DES)

Review of Confidentiality Requirements

27. By 12/31/2019, a workgroup of stakeholders should be convened, including DES, AHCCCS, ADHS, and DCS, to identify potential revisions to state statute and agency policies to allow confidential information sharing between parties while maintaining required privacy and confidentiality protections. The objective of the workgroup should be to minimize the number of investigative interviews (in keeping with a trauma-informed approach) and ensure appropriate monitoring and oversight of agencies and providers. The workgroup's recommendations should be completed by 6/30/2020. (Lead Entity: DES)

Independent Quality Monitoring Process

28. By 12/31/2020, as an adjunct to the quality monitoring and oversight activities conducted by state agencies and providers, AHCCCS and DES should collaborate with community stakeholders to study the Independent Monitoring for Quality (IMQ) processes used in other states and consider their application in Arizona. A description of the IMQ model is provided in Appendix 4. (Lead Entity: AHCCCS)

Licensure of Nursing Supported Group Homes

29. The State should consider legislation to require licensure of nursing supported group home settings reflective of the level of care they are providing. (Lead Entity: ADHS)

Review of Status and Results of Recommendations

30. A Task Force should be convened in late 2020 to review the status and results of these recommendations. (Lead Entity: Governor's Office)

Appendix 1 — Facilitator, Task Force, and Workgroup Members

FACILITATOR

Sharon Flanagan-Hyde, Senior Partner, Flanagan-Hyde Associates

TASK FORCE

1. Nancy Anderson, PhD, CPHQ; Utilization Review/Quality Management, Pascua Yaqui Tribe
2. Lindsay Ashworth; Sexual Violence Response Manager, Arizona Coalition to End Sexual and Domestic Violence (as of July 2019)
3. Representative Nancy Barto; Arizona Legislative District 15
4. Vicki Began, RN, MN; Chief Executive Officer, San Carlos Apache Healthcare Corporation
5. John Black; Chair, Arizona Developmental Disabilities Planning Council
6. Colby Bower, MSM; Assistant Director, Policy and Intergovernmental Affairs, Arizona Department of Health Services
7. Senator Kate Brophy McGee; Arizona Legislative District 28
8. Mark Carroll, MD; Chief Health Officer, NARBHA Institute
9. Maureen Casey; Senior Advisor to the Director's Office, Arizona Department of Economic Security
10. Cara Christ, MD, MS; Director, Arizona Department of Health Services
11. Christina Corieri, JD; Senior Policy Advisor, Arizona Governor's Office
12. Megan Cox; Partner, Lincoln Strategy Group; Family Member
13. Asim Dietrich, JD; Staff Attorney, Arizona Center for Disability Law
14. Dana Flannery; Assistant Director, Division of Community Advocacy and Intergovernmental Relations, Arizona Health Care Cost Containment System
15. Stuart Goodman; Principal, Goodman Schwartz Public Affairs
16. James (Charlie) Green, PhD; Assistant Director, Division of Developmental Disabilities, Arizona Department of Economic Security (through June 2019)
17. Emily Jenkins, JD; CEO, Arizona Council of Human Service Providers
18. Gina Judy, MAOM; COO, Easterseals Blake Foundation; Chair, Developmental Disabilities Advisory Council; Member, State Medicaid Advisory Council; Executive Committee, Arizona Association for Providers for Persons with Disabilities
19. Dana Kennedy, MSW; State Director, Arizona AARP
20. Cindy Leach, RN, NHA; COO, CopperSands; Arizona Health Care Association Board Member
21. Jakenna Lebsock, MPA; Clinical Administrator, Division of Health Care Management, Arizona Health Care Cost Containment System
22. Representative Jennifer Longdon; Arizona Legislative District 24
23. Erica McFadden, PhD, MSW; Executive Director, Arizona Developmental Disabilities Planning Council
24. Jon Meyers; Executive Director, The Arc of Arizona

25. Joyce Millard Hoie, MPA; Consultant; Parent; Member, State Medicaid Advisory Council
26. Sean Mockbee; Managing Partner, Sunshine Village Memory Care and Paseo Village Assisted Living
27. Ann Monahan; Board President, Arizona Autism Coalition; Vice President, State and Governmental Affairs, H.O.P.E. Group, LLC
28. Janna Murrell; Assistant Executive Director, Raising Special Kids, Parent
29. Phil Pangrazio; President & CEO, Ability360
30. Suzanne Pfister; President & CEO, Vitalyst Health Foundation
31. Ellen Poole; Representative, MGA Home Health Care
32. Sean Price; Deputy Director of Programs, Arizona Department of Economic Security (through June 2019)
33. David Reede; Executive Director, San Carlos Apache Health and Human Services
34. Denise Resnik; Co-Founder and Emeritus Board Member, Southwest Autism Research & Resource Center; Founder, First Place; Parent
35. Virginia Rountree, Assistant Director, Division of Health Care Management, Arizona Health Care Cost Containment System
36. Kim Russell; Executive Director, Arizona Advisory Council on Indian Health Care
37. Sara Salek, MD; Chief Medical Officer, Arizona Health Care Cost Containment System
38. Wendy Shaw; CEO, AIRES, LLC; Vice Chair, Arizona Association for Providers for Persons with Disabilities
39. Shelli Silver; Deputy Director for Health Plan Operations, Arizona Health Care Cost Containment System
40. Jami Snyder, MA; Director, Arizona Health Care Cost Containment System
41. Connie Thompson RN, BSBA; Clinical Care Supervisor for Prior Authorization, Care 1st/WellCare Health Plans
42. Michael Traylor; Director, Arizona Department of Economic Security
43. Heidi Trelease; Director of Residential Operations and Quality Assurance, The Tungland Corporation
44. Jason Vail Cruz; Sexual Violence Policy Coordinator, Arizona Coalition to End Sexual and Domestic Violence (through July 2019)
45. Karen Van Epps; Chair, District Central Independent Oversight Committee; Family member of individual with Down syndrome; Member, Developmental Disabilities Advisory Council
46. David Voepel; CEO, Arizona Health Care Association
47. Debra Wertzberger, Deputy Director, Arizona Department of Economic Security (as of June 2019)

Members of Workgroups (In Addition to Task Force Members)

1. Anne Atkins; Family Advocate
2. Sylvia Balistreri; KC Pagels & Associates

3. Kathy Ber, MEd; Legislative Liaison, Arizona Department of Economic Security
4. Cody Conklin-Aguilera, MD, FAAP; Chief Medical Officer, Office of Chief Medical Officers, Arizona Department of Economic Security/Division of Developmental Disabilities
5. Diedra Freedman, JD; Board Secretary/Treasurer, Arizona Autism Coalition; Parent
6. Heather Friebus; Vice President, Arizona Health Care Association; Administrator, Devon Gables
7. Katie Griffith; Self-Advocate
8. Matt Ham; President, Arizona Health Care Association; Southwest Division Vice President, Life Care Centers of America
9. Sarah Hauck; Workforce Development Administrator, Mercy Care
10. Kay Huff; Director of Quality and Regulatory Services, Arizona Health Care Association
11. G'Kyshia Hughes; Family Member
12. Susan Immel; Community Member, Special Education Teacher
13. Susan Junck; Bureau Chief, Office of Individual and Family Affairs, Division of Community Advocacy and Intergovernmental Relations, Arizona Health Care Cost Containment System
14. Bill Kennard; Administrator, Office of Healthcare Workforce Development, Arizona Health Care Cost Containment System
15. Jennifer Kirchen; Deputy Assistant, Department of Economic Security/Division of Aging and Adult Services (DAAS)
16. Allison Kjer, MEd; Workforce Development Administrator, UnitedHealthcare Community Plan
17. Katherine Lemke; Health Plan Trainer/Workforce Development Administrator, Banner University Health Plans
18. Tracy Lopes; Policy Advisor, Democratic Caucus, Arizona House of Representatives
19. Cynthia Macluskie; Autism Society of Greater Phoenix; Parent
20. Emily Mercado; Majority Policy Advisor, Arizona House of Representatives
21. Kimberly Mozes; DES/DDD/HCS/Nursing Program Manager (Healthcare Services Administrator)
22. Son Yong Pak; Parent
23. Barb Picone; Program Manager, Division of Developmental Disabilities, Arizona Department of Economic Security
24. Melanie Richards; Legislative Liaison, Arizona Department of Economic Security
25. J.J. Rico, JD; CEO, Arizona Center for Disability Law
26. Nigel Santiago; Executive Director, Haven of Phoenix
27. Shannon Shiver; Quality Manager, Division of Fee for Service Management, AHCCCS

Appendix 2 — Potential Toolkit Components

Toolkits will be available in multiple languages and customized for different cultures. Representatives of the target audiences will be included in development of content and strategies for dissemination. The following list of potential components is not prescriptive. If a resource requires a public process or legislative approval, appropriate steps will be taken.

Toolkit for Individual with I/DD, Families, and Guardians

- Recognizing Signs & Symptoms of Abuse, Neglect, and Exploitation (easy-to-understand one-page handout)
- Prevention Resources
- Information about accessing sexuality education resources for adults focused on abuse prevention (the Toolkit would not endorse or provide a specific curriculum)
- Incident Decision Tree
- APS Flow Chart
- DDD Quality Management Flow Chart
- Stabilization & Recovery Resource Packet with information about supportive services for the individual and families/guardians

Toolkit for Staff

- Recognizing Signs & Symptoms of Abuse, Neglect, and Exploitation (easy-to-understand one-page handout)
- Prevention Resources
- Information about accessing sexuality education resources for adults focused on abuse prevention (the Toolkit would not endorse or provide a specific curriculum)
- Incident Decision Tree
- APS Flow Chart
- DDD Quality Management Flow Chart
- Trauma-Informed Care Overview
- Stabilization & Recovery Resource Packet with information about supportive services for staff

Toolkit for Providers

- Sample Abuse/Neglect Prevention Policies
- Best practices, resources, and implementation strategies to promote an abuse-free environment
- Information about accessing sexuality education resources for adults focused on abuse prevention (the Toolkit would not endorse or provide a specific curriculum)
- Incident Decision Tree
- APS Flow Chart
- DDD Quality Management Flow Chart

- Trauma-Informed Care Overview
- “Recommended Guidelines for a Coordinated Community Response to Adult Sexual Assault” (September 2018) developed by the Governor’s Office of Youth, Faith and Family and the Arizona Coalition to End Sexual & Domestic Violence

Appendix 3 — Trauma-Informed Approach

The federal Substance Abuse and Mental Health Services Administration (SAMHSA) published *SAMHSA’s Concepts of Trauma and Guidance for a Trauma-Informed Approach* in 2014. It talks about the four “Rs” — key assumptions in a trauma-informed approach:

- All people at all levels of the organization have a basic **realization** about trauma and understand how trauma can affect individuals, families, groups, organizations, and communities.
- All people in organization or system are able to **recognize** the signs of trauma.
- Program, organization or system **responds** by applying principles of trauma-informed approach to all areas of functioning.
- Seek to **resist re-traumatization** of clients and staff. Avoid inadvertently creating stressful or toxic environments that interfere with recovery and well-being.

Six principles of a trauma-informed approach:

1. Safety
2. Trustworthiness and transparency
3. Peer support
4. Collaboration and mutuality
5. Empowerment, voice and choice
6. Cultural, historical, and gender issues

Ten implementation domains for implementing a trauma-informed approach:

1. Governance and leadership
2. Policy
3. Physical environment
4. Engagement and involvement
5. Cross-sector collaboration
6. Screening, assessment and treatment services
7. Training and workforce development
8. Progress monitoring and quality assurance
9. Financing
10. Evaluation

The SAMHSA publication includes sample questions for each domain when implementing a trauma-informed approach.

Appendix 4 — Independent Monitoring for Quality

History and Background

Using advocacy organizations and self-advocates to assist with monitoring and data collection activities was an initiative that began nationally in the 1980s and first emerged in Arizona in the 1990s. In building a system of safeguards and assessing quality of life for individuals with I/DD, the member and family perspective was needed to bring additional value, integrity, current experience with systems, and transparency to the process.

However, in Arizona only nominal efforts were made to implement family and self-advocates in monitoring activities. The ARC of Arizona had one small contract that was initially administered through DDD, but bowing to pressure, it was moved out of the Division, and eventually phased out completely.

Currently in Arizona, DDD contracts with a family advocacy organization to collect data on National Core Indicators (NCI). Pilot Parents of Southern Arizona collects data from surveys with DDD members and their families in various settings via mail and in-person interviews. There are no monitoring activities of the various settings that directly engage self-advocates or family members of individuals with I/DD.

An Example: Pennsylvania- Monitoring and Data Collection

Pennsylvania (PA) is a state in which both data collection and monitoring activities are conducted with stakeholder participation. Along with the NCI, which is not considered by PA stakeholders to be comprehensive enough, the Independent Monitoring for Quality (IMQ) process is staffed by self-advocates and families.

Agency Oversight and Advocacy Engagement

The backbone organization in PA is the Division of Developmental Services through a contract with the University Center for Excellence in Developmental Disabilities (UCEDD) at Temple University. The interviews are conducted in each of Pennsylvania's 48 county Mental Health/Intellectual Disabilities programs by 38 select, independent programs throughout the state. The contracted agencies for IMQ cannot be service providers. However, provider agencies are represented and included in the IMQ planning process. Interview teams, each including a person with a disability or a family member of a person with a disability, are carefully selected and thoroughly trained before the interviewing begins. They complete over 5,000 assessments annually.

The Institute on Disabilities at Temple University developed the program along with stakeholders, and it created the survey, provides training and technical assistance to the interviewers, analyzes the data, and produces an annual statewide summary report along with reports for each county program.

Appendix 5 — 2019 Legislation Summary

Licensure

SB 1211 — Laws 2019, Chapter 133: Requires licensure of ICF/IIDs by the Arizona Department of Health Services by 1/1/2020 and eliminates deemed status for ICFs. This closes a licensing loophole; previously, these facilities were exempt from state licensing requirements.

Background Checks

SB 1211 — Laws 2019, Chapter 133: Requires a DCS Central Registry background check or APS Registry background check for any person who is employed or seeking employment in a position that provides direct services to children or vulnerable adults. The bill also increases the notification between DES and ADHS regarding actions taken in relation to ICF/IIDs.

SB 1247 — Laws 2019, Chapter 134: The list of purposes for which information contained in the DCS Central Registry may be used is expanded to provide information to licensees that do not contract with the state regarding persons who are employed or seeking employment to provide direct services to children in a licensed residential care institution. Beginning on the effective date of this legislation, licensees that do not contract with the state and that employ persons who provide direct services to children in a licensed residential care institution are required to submit to DCS information necessary to conduct Central Registry background checks. ADHS is prohibited from accepting an accreditation report in lieu of any licensure or compliance inspection of a residential facility providing behavioral health services to children. This removed the “deemed status” designation for child residential behavioral health facilities.

Fingerprint Clearance Card

SB 1537 — Laws 2019, Chapter 135: Each person, whether paid or not, who is licensed by DCS, is employed by a DCS licensee, is a DCS contractor that provides services directly to juveniles or vulnerable adults, or is an adult working in a group home, residential treatment center, shelter, or other congregate care setting is required to have as a condition of employment a valid fingerprint clearance card or must apply for a fingerprint clearance card within seven working days after being employed.

Assisted Living Caregivers

SB 1244 — Laws 2019, Chapter 280: By 6/1/2020, the Board of Examiners of Nursing Care Institution Administrators and Assisted Living Facility Managers is required to prescribe rules for assisted living facility caregivers that are consistent with the training, competency, and test methodology standards developed by the AHCCCS Administration for in-home direct care workers. A person who successfully completes the training and competency requirements developed by the AHCCCS Administration for in-home direct care workers satisfies the training requirements for assisted living facility caregivers, except for medication administration training required by the assisted living facility caregiver's scope of practice.

Adult Protective Services

SB 1538 — Laws 2019, Chapter 321: Establishes the “APS central intake unit” as a unit of specialized staff within APS that is responsible for receiving and screening reports of alleged abuse, neglect, or exploitation of vulnerable adults and making the necessary referrals. APS is

authorized to establish a multidisciplinary APS team to develop resources for prevention, intervention, and treatment to better meet the community’s needs for adult protection services. The list of persons with a duty to report a reasonable belief that a vulnerable adult has been the victim of abuse, neglect, or exploitation is expanded to include various health care and emergency personnel and employees of DES. Unless otherwise provided by law, all personally identifying information concerning any person who is involved in an APS program, including the reporting source’s identity, other than a perpetrator against whom an allegation of abuse, neglect, or exploitation has been substantiated, and all information that is gathered or created by APS and that is contained in APS records is confidential and may not be released except as specifically provided in the legislation. APS employees are added to the list of persons who may file an affidavit to request county officers and state agencies prohibit access to that person’s residential address and telephone number contained in certain public records, and who must be notified of the expiration of restrictions on related public records.

Financial Exploitation

SB 1483 — Laws 2019, Chapter 221: If a “qualified individual” (defined) reasonably believes that financial exploitation of an eligible adult may have occurred, may have been attempted, or is being attempted, the individual is permitted to notify APS and the Corporation Commission. An individual who in good faith discloses information under this allowance is immune from administrative or civil liability that might otherwise arise from the disclosure. A broker-dealer or investment adviser is authorized to delay a disbursement from an account of an eligible adult or an account on which an eligible adult is a beneficiary if the broker-dealer, investment adviser, or qualified individual reasonably believes that the requested disbursement may result in financial exploitation of an eligible adult, and the broker-dealer or investment adviser takes a list of specified actions, including notifying parties of the delay. A broker-dealer or investment adviser is required to provide access to or copies of records that are relevant to the suspected or attempted financial exploitation of an eligible adult to APS and law enforcement.

Electronic Monitoring

HB 2117 — Laws 2019, Chapter 226: A service provider that operates a group home or an intermediate care facility for persons with an intellectual disability is permitted to install “electronic monitoring device” (defined) in common areas. The service provider is required to establish policies regarding the use of electronic monitoring and the policies must include a list of specified provisions. The policies must be approved by ADHS prior to installation. The DES Director is required to adopt rules regarding the use of electronic monitoring in Group Homes and ICFs.

Sexual Assault Protective Order

SB 1250 — Laws 2019, Chapter 118: A person is permitted to file a verified petition with a magistrate, justice of the peace, or superior court judge for a sexual assault protective order, and requirements for the petition are established. A fee cannot be charged for filing a petition or for service of process. The court is required to issue a protective order if the court determines that there is reasonable cause to believe the defendant engaged in sexual contact with the plaintiff without consent within the past year or within a longer period of time if the

court finds that good cause exists to consider a longer period. Specifies actions the court is permitted to take if the court issues a sexual assault protective order. Establishes requirements for service of a sexual assault protective order.

Statute of Limitations for Acts Against Minor Victims

HB 2466 — Laws 2019, Chapter 259: Establishes an emergency measure that creates a statute of limitations of 12 years after a plaintiff reaches 18 years of age for civil lawsuits involving minor victims of unlawful sexual conduct and sexual contact. It allows victims above the age of 32 otherwise time-barred until December 31, 2020 to bring their civil claims as outlined.

Appendix 6 — Selected Resources

- Identifying, Reporting, and Preventing Abuse and Neglect of Persons Receiving Services from the Division of Developmental Disabilities (DDD), A Self-Advocacy Guide for Family, Friends, and Guardians, Arizona Center for Disability Law, <https://www.azdisabilitylaw.org/guides/#division-of-development-disabilities-ddd>
- Sexual Abuse of Arizonans with Developmental and Other Disabilities, 2019 Legislative and Regulatory Recommendations for Prevention, Arizona Developmental Disabilities Planning Council, https://addpc.az.gov/sites/default/files/media/2019%20ADDPC%20recomendations%20on%20preventing%20abuse_2.pdf
- Data on APS cases involving individuals with developmental disabilities is available at <https://des.az.gov/services/basic-needs/adult-protective-services>
- Trauma Informed & Developmentally Sensitive Services for Children: Competencies for Effective Practice, The Multiplying Connections Initiative, Health Federation of Philadelphia, https://vtt.ovc.ojp.gov/ojpasset/Documents/MH_Compencies_Of_Trauma_Informed_Care-508.pdf
- Resource Sharing Project
 - Serving Sexual Assault Survivors with Disabilities, <http://www.resourcesharingproject.org/serving-sexual-violence-survivors-disabilities>
 - Eight Step Advocacy Plan for Deaf and Hard of Hearing Survivors of Sexual Assault, <http://www.resourcesharingproject.org/eight-step-advocacy-plan-deaf-and-hard-hearing-survivors-sexual-assault>
- Arizona Recommended Guidelines for a Coordinated Community Response to Adult Sexual Assault, https://www.acesdv.org/wp-content/uploads/2018/11/FINAL_2018-AZ-Guidelines-for-a-Coordinated-Community-Response-to-Adult-Sexual-Assault.pdf
- Abuse-Free Environment
 - Best Practices to Promote and Abuse Free Environment, <https://www.justicecenter.ny.gov/best-practices-abuse-free-environment>
- Division of Developmental Disabilities Statewide Member and Family Forums 2019, <https://des.az.gov/services/disabilities/developmental-disabilities/community-resources/forum-reports>

Appendix 7 — Statistics and Definitions

Statistics

Arizona’s estimated population in 2018 was 7,171,646 people, with 17.5% age 65 and over.² The state has 22 Tribal Nations.³ Based on 2017 Behavioral Risk Factor Surveillance System (BRFSS) data, the Centers for Disease Control and Prevention estimated that 25.8% of adults in Arizona have some type of disability.⁴ Functional disability data includes:⁵

- Mobility 12.6%
- Cognition 11.2%
- Independent living 6.8%
- Hearing 5.9%
- Vision 4.5%
- Self-care 3.3%

The 2019 DDD Family Support Annual Report includes the following statistics:⁶

Eligible Members by Funding Source

- Arizona Long Term Care (ALTCS): 34,182
- Targeted Support Coordination (TSC): 4,884
- State Only (Non-ALTCS): 3,865

People Served by Residence

- Live at home: 88.66%
- Group Home: 7.41%
- Adult Developmental Home: 3.10%
- Child Developmental Home: 0.46%
- Institution (ICF-IID or SNF): 0.35%
- Assisted Living Center: 0.02%
- Behavioral Health Residential Facility: 0.01%

Definitions used by APS and other sources and operative for this report are as follows:⁷

- A **vulnerable adult** is an individual who is 18 years or older who is unable to protect him/herself from abuse, neglect, or exploitation by others because of a physical or mental impairment. This includes individuals with an intellectual/developmental

² <https://www.census.gov/quickfacts/AZ>

³ <https://statemuseum.arizona.edu/programs/american-indian-relations/tribes-arizona>

⁴ <https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/arizona.html>

⁵ <https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/arizona.html>

⁶ <https://des.az.gov/digital-library/ddd-family-support-program-annual-report-2019>

⁷ Arizona Adult Protective Services, <https://des.az.gov/services/aging-and-adult/adult-protective-services/arizona-adult-protective-services-definitions>

disability (I/DD). An individual over the age of 65 is not automatically a vulnerable adult simply because of his/her age.

- **Abuse** is intentional infliction of physical harm, injury caused by negligent acts of omission, unreasonable confinement, and/or sexual abuse or sexual assault. Signs of abuse include, but are not limited to: unexplained bruises, welts, sores, cuts or abrasions in places they would normally not be expected; bruising and other injuries may be in different stages of healing; bruising or other markings reflect the shape of the objects used to inflict the injuries, e.g., electrical cord or belt buckles, etc.; bilateral bruising on upper arms from shaking; fractures in different stages of healing; cigar and cigarette burns; submersion burns, e.g., sock like, glove like, doughnut like shaped on buttocks (can also be patterned like objects used, i.e., electric burner); rope burns on arms/wrists, legs/ankles from improperly tying or bandaging the individual.
- **Neglect** is the deprivation of food, water, medication, medical services, shelter, supervision, cooling, heating, or other services necessary to maintain a vulnerable adult's minimum physical or mental health. Signs of neglect include but are not limited to bedsores (pressure sores); unkempt, dirty, body odor, feces on body; clothing is insufficient or inappropriate for the weather; fleas and lice on individual; malnourished and dehydrated; little or no food available; soiled or urine-soaked bedding.
- **Exploitation** is the illegal or improper use of a vulnerable adult's resources for another's profit or advantage.
- **Financial Exploitation** is the wrongful or unauthorized taking, withholding, appropriating, or use of money, assets, or property of a vulnerable adult, or any act or omission taken by a person, including through the use of a power of attorney, guardianship, or conservatorship of vulnerable adult, to either: 1) obtain control through deception, intimidation, or undue influence over the vulnerable adult's money, assets, or property to deprive the eligible adult of the ownership, use, benefit, or possession of the eligible adult's money, assets, or property; and/or 2) convert money, assets, or property of the vulnerable adult to deprive the vulnerable adult of the ownership, use, benefit, or possession of the vulnerable adult's money, assets or property. Signs of financial exploitation include but are not limited to: accompanied by a stranger to the bank who encourages them to withdraw large amounts of cash; accompanied by a family member or other person who seems to coerce them into making transactions; individual not allowed to speak for themselves or make decisions; implausible explanation about what they are doing with their money; concerned or confused about "missing" funds in their accounts; neglected or receiving insufficient care given their financial status; isolated from others, even family members; unable to remember financial transactions or signing paperwork.
- **Self-neglect** is an adult's inability due to physical or mental impairment or diminished capacity, to perform essential self-care tasks, including, but not limited to: obtaining essential food, clothing, shelter, and medical care; obtaining goods and services necessary to maintain physical health, mental health or general safety; managing one's own financial affairs. (Note: This is not a legal definition.)

- **Intellectual and developmental disabilities (I/DDs)** are disorders that are usually present at birth and that negatively affect the trajectory of the individual’s physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems. Intellectual disability starts any time before a child turns 18 and is characterized by problems with both: intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and adaptive behavior, which includes everyday social and life skills. The term developmental disabilities is a broader category of often lifelong disability that can be intellectual, physical, or both. I/DD is the term often used to describe situations in which intellectual disability and other disabilities are present.⁸
- **Sexual assault** is a crime of violence, anger, power, and control where sex is used as a weapon against the victim. It includes any unwanted sexual contact or attention achieved by force, threats, bribes, manipulation, pressure, tricks, or violence. It may be physical or non-physical and includes rape, attempted rape, incest and child molestation, and sexual harassment. It can also include fondling, exhibitionism, oral sex, exposure to sexual materials (pornography), and the use of inappropriate sexual remarks or language.⁹
- **Sexual abuse** is similar to sexual assault but is a pattern of sexually violent behavior that can range from inappropriate touching to rape. The difference between the two is that sexual assault constitutes a single episode whereas sexual abuse is multiple episodes.
- **Facility** is any entity that serves vulnerable individuals.

⁸ U.S. Dept. of Human Services, National Institutes of Health, <https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default>

⁹ The Arc, <https://www.thearc.org/what-we-do/resources/fact-sheets/sexual-violence>.