Meeting Minutes

April 11, 2022

Certified Professional Guardianship and Conservatorship Board

Monday, April 11, 2022
Zoom Meeting
9:00 a.m. – 1:00 p.m.

MEETING MINUTES	
Members Present	**Members Absent**
Judge Diana Kiesel, Chair	Commissioner Cadine Ferguson-Brown
Judge Grant Blinn[1]	
Judge Robert Lewis	
Ms. Kristina Hammond	
Ms. Lisa Malpass[2]	**Staff Present**
Ms. Melanie Maxwell	Ms. Stacey Johnson
Mr. William Reeves	Mr. Christopher Stanley
Dr. K. Penney Sanders	Ms. Kathy Bowman
Mr. Dan Smerken	Ms. Thai Kien
Ms. Susie Starrfield	Mr. Samar Malik
Ms. Amanda Witthauer	Ms. Maureen Roberts
Dr. Rachel Wrenn[3]	Ms. Sherri White

Guests – See last page

1. Meeting Called to Order

Judge Diana Kiesel called the April 11, 2022 Certified Professional Guardianship and Conservatorship Board meeting to order at 9:04 a.m.

2. Welcome, Roll Call & Approval of Minutes

Judge Kiesel welcomed all present.

Motion: A motion was made and seconded to approve the March 14, 2022 Board meeting minutes as written. The motion passed.

3. Chair's Report

The Standards of Practice Committee must meet constantly to process incoming grievances. Board members were reminded to review posted grievance materials over the weekend prior to Board meetings.

Board Committees will begin posting their meeting minutes to the Guardian Portal website once AOC has that system in place. Until then, Stakeholders were encouraged to contact Stacey Johnson for meeting minutes if desired.

[1] Judge Blinn joined the meeting at 9:17 a.m.
[2] Ms. Malpass joined the meeting at 9:09 a.m.
[3] Dr. Wrenn joined the meeting at 9:06 a.m.

Meetings planned with the Diversity, Equity and Inclusion (DEI) Committee and University of Washington Continuum College have been rescheduled. Updates will be provided at the next Board meeting.

Stakeholders have been encouraged to reach out to address the Board quarterly at the longer meetings.

4. Staff Update

Stacey Johnson gave an update on current staff and the committees they support. Sherrie White staffs the Applications Committee, Rhonda Scott staffs the Standards of Practice Committee, Kay King staffs the Regulations Committee and Linda Vass staffs the DEI and Education Committees.

Ms. Johnson reported numerous updates have been made to the Guardianship Portal website, and fact sheets have been created regarding the UGA. Pattern Forms have been updated, and a new system has been put in place for tracking grievances under the UGA timeline.

The Adult Lay Guardian training has been updated, and is now also available in Spanish.

Between 50-100 inquiries monthly are answered by staff. Many of these inquiries are received from Lay Guardians regarding changes brought by the new law.

Staff has been working from home now for two full years due to COVID, resulting in increased efficiencies including a big shift towards electronic documentation from paper. AOC Leadership plans to have some staff begin returning to the office as early as June.

5. Public Comments

Stakeholders and members of the public were invited to address the Board at this time. There were none wishing to speak.

6. Grievance Report

Staff provided a brief overview of the 2021 Certified Professional Guardianship Board's Annual Report, which has been posted to the Guardian Portal website. Staff also reviewed the status of grievances at month-end March 2022.

Staff was asked the number of currently active Certified Professional Guardians, which is 258 individuals.

7. Mr. Mark Vohr on behalf of WAPG

Mr. Mark Vohr introduced himself as president of Washington Association of Professional Guardians (WAPG) and said WAPG appreciated the inclusion of its input on recent changes to Regulation 400 Standards of Practice. WAPG provides trainings for Certified Professional Guardians and Conservators, and Mr. Vohr suggested if WAPG's trainings are attended, a CPGC can complete all Continuing Education Requirements under Regulation 200. Mr. Vohr said he also mentors members of WAPG

via a listserv. WAPG has plans to produce a weekly webinar with topic speakers and CPGs will be encouraged to bring questions and concerns, as there are CPGs out there with more experience than the Board. WAPG is a guest lecturer at the UW Certificate Program. WAPG lobbies the legislature and participated as a stakeholder bringing the UGA into being. Everything is getting a lot better with the UGA, and less restrictive alternatives is a major component of the UGA. Mr. Vohr was also involved in the production of new forms. Mr. Vohr and Judge Kiesel have discussed a mentorship program, and while WAPG is hugely supportive, it doesn't have the "horsepower" to manage that. There is concern of liability for members of WAPG, and there has not been membership from WAPG interested in pursuing a mentorship program.

Judge Kiesel asked Mr. Vohr if WAPG is still providing webinars and seminars rather than one-on-one training. Mr. Vohr answered WAPG and other organizations run by professional guardians are putting on regular trainings for professional guardians. Those trainings are comprehensive and approved for credit by the board. Together, these trainings provide for a majority of the training opportunities for professional guardians and are very effective and informative. Consequently, professional guardians have a long track record of providing excellent trainings to professional guardians. When we turn to the context of whether CPGs should also serve as individual mentors, the concern would be that the quality of a mentorship program depend greatly on the quality of the mentors. A person may be a very good CPG, but may not be a good individual mentor. Any mentorship program hoping to be successful, would need a mechanism for selecting, guiding and training mentors. WAPG does not have the staffing to perform that function.

Judge Kiesel next asked about the membership at WAPG and how do non-members tap the wealth of knowledge. What is WAPG's outreach? Mr. Vohr answered there are currently 80 members. Jamie Shirley and Malinda Frey at the UW Certificate program do give WAPG a spot every year to speak to students, and WAPG tries to reduce the barriers to membership by keeping the membership fee low. WAPG does not reach out to CPGs, they are expected to contact WAPG if interested.

Dr. Sanders asked Mr. Vohr if WAPG is doing anything to work with insurance carriers, such as Dominion, Lloyds of London, as this is very expensive. Dr. Sanders said some carriers have eliminated coverage for medical decision making, including for less-restrictive alternatives, such as power of attorney. Mr. Vohr answered WAPG is not currently looking at issues around insurance, but agreed it would be a good idea for WAPG to get behind this, and that issues around death with dignity adds a layer of complexity to insurance and exposure to liability.

WAPG wants to participate and be present in what the Board is doing. The elephant in the room is that the relationship with the Board has been contentious in the past and Mr. Vohr wants to improve that relationship. WAPG recognizes the Board's hard work in relation to changes brought by the UGA. Mr. Vohr proposed the idea of having professional guardians participate on the committee level as ad-hoc and non-voting. Mr. Vohr said he was surprised that no one from WAPG was involved in writing the Lay Guardian training, as WAPG has something to contribute. Mr. Vohr asked the Board if it feels it has any role in supporting professional guardians. Judge Kiesel replied the Board follows GR 23, Regulations, etc. and has attempted to make the Board more accessible to CPGs, such as including comments submitted by CPGs. Mr. Smerken said the Board's role is very explicitly set out in GR 23 and he does not believe the Board has any role with lay guardians. Mr. Vohr commented that past staff to the Board included

his input. As president of WAPG he has to "dig" people out from past experiences with the Board.

Judge Lewis remarked that WAPG's proposed participation on Board Committees, such as Applications or Standards of Practice would not be appropriate. However, if WAPG is interested in becoming involved with Education, DEI or Regulations Committees, it is welcome to submit public comments. Mr. Vohr believes there is precedent for involving WAPG in committees, as he has personally been asked to join a Conflicts Review Committee panel in the past.

Ms. Malpass said CPGs are welcome to participate on the Education Committee, and she has been a big fan of WAPG both personally and professionally. As a lawyer, she strives to remain objective, but informally, her experience is that at every committee meeting she has attended, the Board has shown great respect for CPGs in Washington State.

Mr. Vohr maintains that WAPG has so much experience to contribute to the Board and they can maintain confidentiality if they can participate in the Board's work, and challenged the objectivity of the Board, focusing on the "feet on the ground" expertise of CPGs. WAPG wishes to help the Board, and even those CPGs who are not members of WAPG, by being involved at the committee level. He again mentioned working with previous staff. Judge Kiesel observed that it is interesting that CPGCs are taking a more critical look at their profession.

Staff thanked Mr. Vohr for his presentation to the Board. Staff reminded Mr. Vohr that while the Board was not involved in producing the Lay Guardian training, this training was not updated in a vaccum. It was updated by the training coordinator and reviewed by the Superior Court Judges' Association's Guardianship and Probate Committee. Mr. Vohr gave a shout out to the training coordinator for all the hard work accomplished, however, in the past, Elder Law had been given an opportunity to be involved in producing Lay Guardian training. Staff noted that there were time constraints on making the training available and invited anyone who wishes to provide comments on the training to please submit their input. The Lay Guardian Training is on a new platform and easy to update and edit.

8. Executive Session (Closed to Public)

9. Reconvene and Vote on Executive Session Discussion (Open to Public)

On behalf of the Applications Committee, Judge Robert Lewis presented the following applications for certification. The Application Committee abstained.

Motion: A motion was made and seconded to conditionally approve Jayson Hills' application for certification, conditioned on the completion of mandatory training, with transferable skills in social services. The motion passed.

Motion: A motion was made and seconded to deny Emily McCarty's application for certification, for insufficient transferable experience. Mr. Reeves opposed. The motion passed.

Motion: A motion was made and seconded to conditionally approve Kevin Wanjohi's application for certification, conditioned on the completion of

mandatory training, with transferable skills in social services and health care. The motion passed.

On behalf of the Standards of Practice Committee, Judge Grant Blinn presented the following grievances for Board action. Members of the Standards of Practice Committee abstained.

Motion: A motion was made and seconded to refer grievance 2022-023 to Board staff for further investigation. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-024 for no jurisdiction. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-025 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-026 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-027 as incomplete. Judge Lewis opposed. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-028 for no jurisdiction. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-029 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-030 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-031 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-032 for no jurisdiction. The motion passed.

10. Wrap Up/Adjourn

With no other business to discuss, the April 11, 2022 CPGC Board meeting was adjourned at 12:10 p.m. The next Board meeting will take place via Zoom teleconference on Monday, May 9, 2022 beginning at 8:00 a.m.

Recap of Motions:

MOTION SUMMARY		STATUS
Motion:	A motion was made and seconded to approve the minutes of the March 14, 2022 Board meeting as written.	Passed
Motion:	A motion was made and seconded to conditionally approve Jayson Hills' application for certification, conditioned on the completion of mandatory training, with transferable skills in social services	Passed

Motion:	A motion was made and seconded to deny Emily McCarty's application for certification, for insufficient transferable experience. Mr. Reeves opposed.	Passed
Motion:	A motion was made and seconded to conditionally approve Kevin Wanjohi's application for certification, conditioned on the completion of mandatory training, with transferable skills in social services and health care.	Passed
Motion:	A motion was made and seconded to refer grievance 2022-023 to Board staff for further investigation.	Passed
Motion:	A motion was made and seconded to dismiss grievance 2022-024 for no jurisdiction.	Passed
Motion:	A motion was made and seconded to forward complete grievance 2022-025 to the Superior Court	Passed
Motion:	A motion was made and seconded to forward complete grievance 2022-026 to the Superior Court.	Passed
Motion:	A motion was made and seconded to dismiss grievance 2022-027 as incomplete. Judge Lewis opposed.	Passed
Motion:	A motion was made and seconded to dismiss grievance 2022-028 for no jurisdiction.	Passed
Motion:	A motion was made and seconded to forward complete grievance 2022-029 to the Superior Court.	Passed
Motion:	A motion was made and seconded to forward complete grievance 2022-030 to the Superior Court.	Passed
Motion:	A motion was made and seconded to forward complete grievance 2022-031 to the Superior Court.	Passed
Motion:	A motion was made and seconded to dismiss grievance 2022-032 for no jurisdiction.	Passed

Guests:

Brenda Morales
Chris Neil
Clif Messerschmidt
Deborah Jameson
Denise Meador
Glenda Voller
Jan Low
Jenifer Mick
Karen Klem
Mark Vohr
Mary Shobe
Neil & Neil
Puget Sound Guardians
Samantha Hellwig
Scott Malavotte

Meeting Minutes

May 9, 2022

Certified Professional Guardianship and Conservatorship Board

Monday, May 9, 2022
Zoom Meeting
8:00 a.m. – 9:00 a.m.

DRAFT MEETING MINUTES	
Members Present	**Members Absent**
Judge Diana Kiesel, Chair	Commissioner Cadine Ferguson-Brown
Judge Grant Blinn	
Judge Robert Lewis	**Staff Present**
Ms. Kristina Hammond[1]	Ms. Stacey Johnson
Ms. Lisa Malpass	Ms. Kathy Bowman
Ms. Melanie Maxwell[2]	Ms. Thai Kien
Mr. William Reeves	Ms. Kay King
Dr. K. Penney Sanders	Mr. Samar Malik
Mr. Dan Smerken	Ms. Maureen Roberts
Ms. Susie Starrfield	Ms. Sherri White
Ms. Amanda Witthauer	Ms. Linda Vass

Guests – See last page

1. Meeting Called to Order

Judge Kiesel called the May 9, 2022 Certified Professional Guardianship and Conservatorship Board meeting to order at 8:01 a.m.

2. Welcome, Roll Call & Approval of Minutes

All present were welcomed and roll was called.

Motion: A motion was made and seconded to approve the minutes of the April 11, 2022 Board meeting as written. The motion passed.

3. Chair's Report

Judge Kiesel reported Dr. Rachel Wrenn has resigned from the Board for personal reasons and commented Dr. Wrenn's knowledge and insight will be missed. The Diversity, Equity and Inclusion (DEI) Committee is working on a proposal for the Board to approve a panel of experts for presentation at one of the Board's long meetings. Ms. Malpass has agreed to serve on the Regulations Committee. The Standards of Practice (SOP) Committee has been a very busy committee since January, and special thanks go to Judge Blinn and Dr. Sanders. The Supreme

[1] Ms. Hammond joined the meeting at 8:05 a.m.
[2] Ms. Maxwell joined the meeting at 8:13 a.m.

Court has reconsidered recent changes to GR23, suspending the portion of the rule making the Board subject to the Open Public Meetings Act. At the June meeting, the Board will review draft language for GR 23 to require the Board to operate under the spirit of the Open Public Meetings Act, but not be subject to the OPMA.

4. Grievance Report

Staff reported 9 grievances were received during the month of April. One grievance was dismissed for no actionable conduct. To date, the Board dismissed 14 grievances received in 2022 as incomplete or for no jurisdiction, 20 grievances have been forwarded to the court and 1 grievance has been assigned to staff for investigation. A total sixty-two (62) grievances are currently unresolved.

5. Regulations Committee

The Board previously approved publication for notice and comment a proposed change to Application Regulation 103 Qualifications, to address the requisite documentation or certification of completion of High School or GED. Two comments were received from stakeholders. It was noted that the Board may wish to invite the stakeholders to address the Board at a future date.

Motion: A motion was made and seconded to approve the proposed change to Regulation 103. The motion passed.

The Board was asked to approve the publication for notice and comment, proposed changes to Certification Maintenance Regulation 708 Voluntary Surrender, to create a process for those retiring from the Certified Professional Guardian and Conservator profession with acknowledgement, and change the terminology from “voluntary surrender” to “termination of certification”.

Motion: A motion was made and seconded to publish for notice and comment proposed changes to Regulation 708. The motion passed.

6. Executive Session (Closed to Public)

7. Reconvene and Vote on Executive Session Discussion (Open to Public)

On behalf of the Applications Committee, Judge Robert Lewis presented the following applications for certified professional guardian and conservator. The Applications Committee abstained.

Motion: A motion was made and seconded to conditionally approve Thelma Clinton’s application, conditioned on the completion of the UW Certification Program, with transferable skills in healthcare and social services. The motion passed.

Motion: A motion was made and seconded to conditionally approve Marina Richardson’s application, conditioned on the completion of the UW Certification Program, with transferable skills in social services. The motion passed.

Motion: A motion was made and seconded to conditionally approve Wendy Werner’s application, conditioned on the completion of the UW Certification Program, with transferable skills in financial. The motion passed.

On behalf of the Standards of Practice Committee, Judge Grant Blinn presented the following grievances for Board action. Members of the Standards of Practice Committee abstained.

Motion: A motion was made and seconded to forward complete grievance 2022-033 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-034 for no jurisdiction. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-035 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-036 for no jurisdiction. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-037 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-038 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-039 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-040 to the Superior Court. The motion passed.

Motion: A motion was made and seconded to dismiss grievance 2022-041 for no jurisdiction. The motion passed.

Motion: A motion was made and seconded to forward complete grievance 2022-042 to the Superior Court. The motion passed.

Judge Grant Blinn presented the following Court Reviews for final Board action. Members of the Standards of Practice Committee abstained.

The Superior Court found in its review of grievance 2022-005, it was filed in other than good faith, attempting to circumvent an existing VAPO, and there was no guardianship in place during the period of alleged issues.

Motion: A motion was made and seconded to dismiss grievance 2022-005. The motion passed.

The Superior Court found in its review of grievance 2022-015, the individual was properly served, and the GAL has determined the individual requires guardianship.

Motion: A motion was made and seconded to dismiss grievance 2022-015. The motion passed.

Judge Grant Blinn presented the reconsideration of grievance 2022-007, previously dismissed as incomplete (unsigned). Members of the Standards of Practice Committee abstained.

Motion: A motion was made and seconded to open an investigation of grievance 2022-007 to be undertaken by Board Staff. The motion passed.

Judge Grant Blinn presented grievance 2020-041, regarding a guardianship filed in Tribal Court. Members of the Standards of Practice Committee abstained.

Motion: A motion was made and seconded to forward grievance 2020-41 to the Tribal Court and be revisited by the Board in no later than 60 days. Judge Lewis opposed, as the grievance should be concurrently investigated by staff. The motion passed.

8. Wrap Up/Adjourn

The May 9, 2022 CPGC Board meeting was adjourned at 9:07 a.m. The next meeting of the Board is on June 13, 2022.

Recap of Motions:

MOTION SUMMARY	STATUS
A motion was made and seconded to approve the minutes of the April 11, 2022 Board meeting as written.	Passed
A motion was made and seconded to approve the proposed change to Regulation 103.	Passed
A motion was made and seconded to publish for notice and comment proposed changes to Regulation 708.	Passed
A motion was made and seconded to conditionally approve Thelma Clinton's application, conditioned on the completion of the UW Certification Program, with transferable skills in healthcare and social services.	Passed
A motion was made and seconded to conditionally approve Marina Richardson's application, conditioned on the completion of the UW Certification Program, with transferable skills in social services.	Passed
A motion was made and seconded to conditionally approve Wendy Werner's application, conditioned on the completion of the UW Certification Program, with transferable skills in financial.	Passed
A motion was made and seconded to forward complete grievance 2022-033 to the Superior Court.	Passed
A motion was made and seconded to dismiss grievance 2022-034 for no jurisdiction.	Passed
A motion was made and seconded to forward complete grievance 2022-035 to the Superior Court.	Passed
A motion was made and seconded to dismiss grievance 2022-036 for no jurisdiction.	Passed
A motion was made and seconded to forward complete grievance 2022-037 to the Superior Court.	Passed

A motion was made and seconded to forward complete grievance 2022-038 to the Superior Court.	Passed
A motion was made and seconded to forward complete grievance 2022-039 to the Superior Court.	Passed
A motion was made and seconded to forward complete grievance 2022-040 to the Superior Court.	Passed
A motion was made and seconded to dismiss grievance 2022-041 for no jurisdiction.	Passed
A motion was made and seconded to forward complete grievance 2022-042 to the Superior Court.	Passed
A motion was made and seconded to dismiss grievance 2022-005.	Passed
A motion was made and seconded to dismiss grievance 2022-015.	Passed
A motion was made and seconded to open an investigation of grievance 2022-007 to be undertaken by Board Staff.	Passed
A motion was made and seconded to forward grievance 2020-41 to the Tribal Court and be revisited by the Board in no later than 60 days. Judge Lewis opposed, as the grievance should be concurrently investigated by staff.	Passed

Guests:

Samantha Hellwig, AAG
Glenda Voller
Chris Neil
Deborah Jameson
Frank Nelson
Katlyn Balsam

Public Comment
Spectrum Institute

Disability and Abuse Project
Disability and Guardianship Project

1717 E. Vista Chino A7-667, Palm Springs, CA 92262
(818) 230-5156 • www.spectruminstitute.org

June 1, 2022

Honorable Steven C. González
Washington Supreme Court
P.O. Box 40929
Olympia, WA 98504-0929

Re: Adoption of ADA-Compliant Mental Health Access Standards by the Certified Professional Guardianship and Conservatorship Board

Dear Chief Justice González:

We are sending this letter and attachments to you and the CPGC Board in advance of our presentation at the Board's meeting on June 13, 2022. As we address the relevance of our recently released Consequences Report to the mental health needs of adults who are living under an order of guardianship, we will be emphasizing the application of the Americans with Disabilities Act.

These materials should help the Board, under the supervision of the Supreme Court, develop standards of practice which protect the rights of protected persons and comply with standards adopted by the National Guardianship Association. They should also assist local courts and fiduciaries to meet their obligations under Title II of the Americans with Disabilities Act.

We have advised the Supreme Court several times regarding the application of the ADA to guardianship proceedings. We submitted a formal ADA complaint which was received but never acted on to our knowledge. With this letter, we are getting more specific by emphasizing that the ADA entitles protected persons to have effective communication and meaningful participation in ongoing guardianship proceedings, including prompt and equal access to mental health services when they are needed. Because guardians are "gatekeepers" to such services for individuals under their care, it is essential that the Board, under supervision of the Supreme Court, have a mechanism in place that maximizes access to mental health services for this vulnerable population. That requires specific standards of practice on this topic, proper training, and effective monitoring mechanisms.

We hope these materials and our upcoming presentation will help the Board fulfill its duties by taking appropriate steps to adopt ADA-complaint standards, training, and monitoring mechanisms to ensure prompt and equal access to mental health services for protected persons when they need it.

Respectfully submitted:

Thomas F. Coleman
Legal Director
tomcoleman@spectruminstitute.org

Christina Baldwin
Mental Health Project Director
christina.baldwin@spectruminstitute.org

cc: CPGC Board Members

CONSEQUENCES

A Report on the Adverse Effects of
Delayed or Denied Mental Health Services to
Adults with Developmental Disabilities

Consequences to the Individual

May 2022

Spectrum Institute

Mental Health Project
Emmi Deckard
Christina Baldwin
Thomas F. Coleman

About Spectrum Institute

Spectrum Institute is a nonprofit organization incorporated in California in 1987. It has 501(c)(3) federal tax exempt status. The organization has engaged in research, education, and advocacy on a variety of civil rights issues affecting populations historically subjected to discrimination and injustice. This has included the LGBT community, single and unmarried adults, victims of hate crimes, abused teenagers, and people with disabilities. Spectrum Institute publishes policy reports and commentaries, files briefs in court cases, and provides expert testimony in connection with pending legislation.

This report is available online at:
https://spectruminstitute.org/consequences-report.pdf

Spectrum Institute
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Mental Health Project
Disability and Guardianship Project

1717 E. Vista Chino A7-384 • Palm Springs, CA 92262
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Date: May 1, 2022

To: Gatekeepers of Mental Health Services for Adults with Developmental Disabilities (Families, Doctors, Guardians, Lawyers, Judges, Health Care Payers & Providers)

Re: A request to: (1) consider the consequences of the delay or denial of mental health services to adults with developmental disabilities; (2) review your existing policies and procedures; (3) make adjustments to improve access

Dear Gatekeepers:

We are writing to share a new publication titled *Consequences: A Report on the Adverse Effects of Delayed or Denied Mental Health Services to Adults with Developmental Disabilities*. Although the delay or denial of prompt access to mental health services may have legal and financial ramifications for those we call "gatekeepers," this report focuses on the consequences to the disabled adults who need but do not obtain such services in a timely manner.

We refer to "gatekeepers" as the professionals and officials who control mental health access for this vulnerable population. Most adults with developmental disabilities lack the understanding, communication skills, or tools to access mental health services on their own. They must depend on others to facilitate this process.

If you are someone that such an adult depends on – a parent, primary care physician, guardian or conservator, court-appointed attorney, judge, service provider, health care payer – we want you to become aware of the consequences to an individual if you fail to secure mental health access for them when they need it. We also want you to be aware that most of them do have such a need, whether it is to treat conditions associated with their disability, or to address conditions arising from acute or chronic mental illnesses, victimization from crime, or the traumatic effects of abuse.

We hope that once you realize how devastating the delay or denial of mental health access can be to such individuals, you will take appropriate steps to improve the policies and practices that guide your role as a gatekeeper to such services. We also invite you to share your views with us on this topic. Please contact Tina Baldwin. (christina.baldwin@spectruminstitute.org)

Best regards,

Thomas F. Coleman
Executive Director

Consequences of Denied or Delayed Mental Health Care for People with Developmental Disabilities

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Foreword

Spectrum Institute serves as a leading policy advocate for individuals with developmental and intellectual disabilities. With increased discourse on issues like conservatorship and mental health education in the United States, it is paramount that the needs of individuals with disabilities are included in our assessment of the mental health landscape.

The report submitted by Emmi Deckard brings much needed attention to barriers associated with delayed or limited access to mental health care for individuals with developmental disabilities. Deckard clearly outlines the prevalence of co-morbid mental health disorders and the need for appropriate mental health services. The report also addresses the paucity of culturally attuned services and professionals to address the unique experiences of folks with developmental disabilities. This lack of access is exacerbated by structural factors like insurance coverage.

As a clinician and researcher, I urge future work to consider multiple identity-based systems. We must also consider how structural barriers related to class and how intersectional identity-based stigma may further impede engaging with the mental healthcare system.

Throughout the COVID-19 pandemic, telehealth practices have increased access to virtual care for folks with transportation concerns, for example. However, this shift has also underscored clear gaps in access to technology and issues related to class and socioeconomic status. These issues are particularly relevant to individuals with disabilities, given 2020 national data from the U.S. Department of Labor (DOL) citing lower full-time employment rates for those with disabilities. Consistent with previous literature, a 2021 report by the Institute for Community Inclusion at UMass Boston found that these employment disparities are even greater for folks with developmental disabilities (Winsor et al., 2021). These structural factors limit access to affordable, comprehensive mental health care.

Furthermore, it is crucial to understand that individuals with disabilities are not a monolithic group. For example, employment disparities are higher for BIPOC individuals with disabilities (Department of Labor, 2020). Such data underscores the reality that every individual holds intersecting identities that influence how they navigate complex systems of power and privilege. Within these systems, structural (e.g., barriers to access, discrimination) and psychological (e.g., stigma, microaggressions) factors impact engagement and utilization of mental health care by minoritized groups, like BIPOC (Black, indigenous, and people of color) and LGBTQ+ communities (Perzichilli, 2020; Green et al, 2020). While little is known about individuals with disabilities at these intersections, further integration of these systems and contexts is essential for future work.

In sum, this report provides valuable insight into barriers to mental health care for individuals with disabilities. Future work will need to explore how systemic experiences (e.g., classism, racism, heterosexism) further impact access to mental health care for those with disabilities within our current context. Adopting this intersectional lens can provide clinicians and policy advocates with a more holistic understanding of factors that impact care.

José R. Rosario,
Advisor to Spectrum Institute's Mental Health Project
January 28, 2022

Introduction

International treaties, federal laws, and state statutes are supposed to provide a safety net to protect the medical rights of our most vulnerable citizens, people with developmental disabilities. These citizens have the right to access a full range of mental health care therapies that people without such disabilities have.

But what are the consequences when the safety net breaks?

Consequences of Delayed or Denied Mental Health Care to Adults with Development Disabilities, written by Emmi Deckard, reveals that there are significant adverse consequences for adults with development disabilities resulting from the delay or denial of necessary mental health therapy. Her paper is the core of this report.

Deckard did not conduct new, independent research. She is sharing existing research. Each one of the papers, articles, and reports that she references stands on its own merit, and from them Deckard describes the population of adults with developmental disabilities, documents how they are at higher risk for mental illnesses and mental conditions, documents how they are at significant risk for abuse of various types, identifies the variety of mental health therapies that are available for this population, reports that qualified therapists are available but not in sufficient numbers, and identifies the barriers that exist to prompt and effective mental health therapy.

What is a delay? Let's say a person, any person, has been sexually abused, and all that is offered as therapy are behavior modification techniques. Then another mental health or a medical problem develops in reaction to the sexual abuse, and the individual acts out as a relief valve. Their anger, their fear, is boiling up inside them but only attempts to suppress the behavior are offered as solutions. A vicious cycle develops. The individual needs a more holistic approach but this isn't happening, and the cycle becomes more complicated and difficult to address as time passes.

Deckard's report raises many issues in the conversation about systemic reform. People in the general population are able to access mental health services through whatever vehicles are available through their healthcare provider, such as Kaiser, Blue Cross, etc. They are able to ask their primary care physician for a referral for mental health services. They are able to access mental health services because they are able to navigate the system to get services and get them promptly.

But most people with developmental disabilities are not able to do this independently because of the nature of the disability. They are thus dependent on others who become the gatekeepers to services. The gatekeeper could be a parent or relative, a conservator or guardian, a primary care physician with whom they already have an established relationship. The later can become involved in several ways. For example, a physician

becomes a gatekeeper to mental health services if their patient has been a victim of abuse and they are experiencing trauma from that. Or the primary care physician learns that their patient with a developmental disability such as Down syndrome is experiencing and exhibiting symptoms of cognitive decline. They know that the person probably isn't aware that they have this problem or that there is a label to put on the problem or that they are entitled to a referral for mental health evaluation and therapy to help them cope with the symptoms to address the underlying issues to help alleviate or minimize the symptoms. The person with a developmental disability is dependent on the people around them to make that happen. When that doesn't happen because the physician, guardian, or other gatekeeper is in denial or doesn't want to spend the time or for whatever reason, there are adverse consequences to the individual with the developmental disability when they don't get those services.

Deckard describes how the adverse consequences of delayed or denied mental health services can be profound and complicated. For example, if a person experiences abuse, the consequences are depression, PTSD, phobia, anxiety or whatever. We know what happens to people who have PTSD. Their lives can be destroyed by the symptoms they exhibit, that it can destroy relationships or their ability to hold down a job. The same could be true for depression or extreme anxiety or other types of mental health symptoms. The individual may not want to leave the house. They may not be able to go outside to get exercise or fresh air. The quality of their life can be destroyed by a mental illness that is untreated. Some people might not care if the individual with developmental disabilities and mental health problems sits in room 24 hours a day watching tv but that is not the quality of life to which they are entitled as a human being. What matters to the individual with developmental disabilities is that their mental health problems are addressed promptly by accessing mental health services available to everyone else.

What happens in the situation for the person with a developmental disability when there are behavioral manifestations such that people around them are uncomfortable or embarrassed and are more concerned with suppressing the behavior than they are about the underlying reasons for the behavior?

Perhaps an applied behavioral analysis specialist enters the picture and then treatment might be all about controlling behaviors. I am not saying there isn't a place for that but if emphasis centers on behaviors disappearing and not on the underlying conditions then we still have the cause of the problem. If all they are trying to do is give them ABC behavior modification this might go on forever. That could result in another mental health problem or other medical problems because all that is being done is forcing them to suppress their behavior when the underlying problem could, for example, be their reaction to sex abuse and they are acting out sexually.

Another scenario is that of the individual who has experienced adverse childhood events (ACEs), which can cause various kinds of trauma. ACEs are underreported and not easily recognized in people with developmental disabilities, and therefore, often remain untreated. If they are not treated with proper forms of mental health therapy, the trauma

can be suppressed and manifest in medical health conditions throughout life. Since this is what happens in the general population who have experienced ACEs, it doesn't require much imagination to understand that for some people with developmental disabilities with traumatic childhood events, the resulting trauma might be more intense for them than it would be for a person without a developmental disability.

Other issues arise in the discussion of adverse consequences. For example, if the person with developmental disabilities has a need for mental health therapy, whose obligation is it to identify that? Whose obligation is it to deal with it in an appropriate, timely way whether it is cognitive therapy or any other therapies available to people without developmental disabilities? Maybe generic therapies that are modified can be part of the treatment plan. Maybe there could be an applied behavioral analysis specialist in additional to a psychologist and psychiatrist. It could be a combination of therapies.

But what if that doesn't happen? What if the need hasn't been identified because people are ignoring it or considering it only a behavioral problem? What if their excuse is they lack the time to deal with it? Or what if they say "there is no one within 10 miles who can deal with it so we are just going to let go of it" when, in fact, there is somebody within 75 miles or somebody who can do it by Zoom? Should these rationales exempt them from the responsibility to ensure prompt and appropriate care for an individual who must depend on them for such care?

Federal and state legislators should create task forces to investigate compliance with the Americans with Disabilities Act (ADA), Medicare, Medicaid, and state agency policies mandating person-centered plans (PCP).

Perhaps many services can be handled at considerable cost savings and more appropriately with person-centered service plans which could result in less restrictive services. It should be kept in mind that pre-existing mental health issues and challenging behaviors can be exacerbated by inappropriate service plans. Person-centered planning is essential for the most effective use of dollars for each individual. When service providers request higher and more expensive levels of services because of mental health or behavior challenges and mental health care services are absent, then there is the possibility of conflict of interest issues. How about making it mandatory that an appropriate mental health professional be involved before more expensive services are approved?

Guardians have a legal duty to secure prompt and effective health care treatment for adults under their care. Relatives who have voluntarily assumed the role of care providers also have legal duties. The failure to secure prompt and appropriate health care, including mental health care, may constitute elder or dependent adult abuse or neglect. Thus, under state law, guardians and voluntary care providers could be subjected to civil or criminal liability for such failures. Then there is the federal ADA statutory scheme. This law requires that the states treat people with disabilities equally with those who do not have disabilities. Excluding people with disabilities from the full range of mental health therapies available to people without disabilities would constitute disability discrimination in violation of the ADA.

Not only are tax dollars at issue but so are civil rights. In September 2019, in a case brought by the Department of Justice (DOJ) against the State of Mississippi, a federal judge ruled that Mississippi was violating the ADA and ordered the state to improve overall delivery of mental health services. The federal judge appointed an overseer to facilitate Mississippi's effort to bring its mental health system into compliance with the ADA. At the end of April 2020, Mississippi legislators finalized a new budget and changes have occurred.

An appropriate legislative committee in each state should request the state's office of financial management or equivalent to review records in a random sample of clients who are receiving services from the state's mental health agency or developmental disability agency. The review should include interviews with clients and their families.

Such a review could include questions such as:

* Has there been a diagnosis of mental health or behavior problems?
* Are services to address mental health or behavior issues being provided? Who is providing them? Have treatment plans been developed by mental health or behavior professionals? Is there ongoing monitoring and evaluation by the professionals?
* Have there been requests for employment and/or residential services or for modification to extant services based on the need to address behavior or mental health challenges?
* Who has made the request: service providers, parents, guardians, psychologists or other mental health professionals?
* If service providers are making the request are they a for-profit business or nonprofit?
* Do service plans meet person-centered criteria, values, and policies of DDA, DSHS, Medicaid, Medicare, and state and federal laws?

The answer to questions such as these will help everyone to have a realistic picture of necessary and potentially excessive expenditures and to evaluate compliance with the ADA as well as the presence of person-centered planning which should identify needed mental health services.

When service providers request higher and more expensive levels of services because of mental health or behavior challenges and mental health care services are absent, then there is the possibility of conflict of interest issues. It is essential that an appropriate mental health professional be involved before more expensive services are approved. This and other problems can be identified that will reduce both the adverse consequences to the individual and the allocation of tax dollars.

More attention should be given to training and standards of practice for attorneys representing people with developmental disabilities. It is impossible for attorneys to do their jobs without a basic understanding of specific disabilities and mental illnesses, and how these two together bring an individual to need legal representation. Deckard's report

is a significant start in helping the legal community understand the adverse consequences of denial or delay in mental health services and to begin the discussion on due process improvements within the legal system to appropriately prepare for these cases.

The disparity between professionals with training to appropriately provide the full range of mental health services to people with developmental disabilities as they do to those without developmental disabilities is a significant problem compounded by the reimbursement from Medicaid and Medicare. The mental health community, including university programs, mental health clinics, doctors, nurses, social workers, housing agencies, etc. need to join the chorus for change and contribute to finding solutions.

We need to stop accepting what is and start creating what should be. We need to get the conversation going and start the activities of systemic reform. The soul of our nation is tied to how well we treat our most vulnerable members.

Hopefully, the report will come into the hands of self-advocates who can use the material to advocate for themselves and/or to contact people who can support their efforts to get help and change the disparity in the delivery of services.

It is our intention to get a vigorous conversation going that ultimately leads to systemic reform nationally and in each state in the delivery of mental health services to people with developmental disabilities. This reform must be compliant with the ADA, increase the number of qualified mental health professionals, improve training, and strengthen monitoring and evaluation criteria for professionals such as attorneys, guardians, physicians, and service providers who work with people with developmental disabilities.

We believe there should be three more reports that ask:

* What are the consequences to their families and others in their network of support when mental health services are denied or delayed?
* What are potential legal consequences that willful or negligent delay or denial for such services can have for those who are gatekeepers, for example, primary care physicians, care providers, guardians, and court-appointed attorneys in guardianship?
* What are potential financial consequences that the deprivation or delay of mental health therapy can have on state and local resources, such as extra burdens being placed on entitlement programs, law enforcement services, and judicial proceedings?

Let's get the conversation going with a view to stimulating the adoption and implementation of long overdue improvements in the delivery of mental health services to adults with developmental disabilities.

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Director
Mental Health Project

Consequences of Delayed or Denied Mental Health Care for Individuals with Developmental Disabilities

By Emmi Deckard

Abstract

This report investigates both the origins and frequency of delayed or denied mental health services to adults with developmental disabilities while also illuminating the significant adverse consequences that can occur to these communities as a result.

People with development disabilities are a vulnerable population with an increased need for mental health services.

This group is also vast and diverse. Approximately 7.38 million individuals in the United States have a developmental disability (DD) as of 2017 [1]. In fact, the prevalence of DD overall is on the rise, resulting in approximately 1 in 6 children between the ages of three and seventeen having a diagnosed DD in the United States today [2]. This increase has been attributed to multiple factors including broadened diagnostic criteria, decreasing stigma, utilization of inclusive language, improved screening processes, increased understanding of neurodevelopment, and improved survival rates of children at high risk for disability [3].

According to the Center for Disease Control and Prevention, the term DD encompasses a group of conditions which are characterized by impaired physical, educational, linguistic, or behavioral development [4]. Intellectual disabilities (ID) are just one category of DD along with autism, attention-deficit hyperactivity disorder, learning disabilities, and more [4]. DDs manifest during various developmental periods and typically last throughout an individual's life [4]. Individuals with DD are an extremely heterogeneous group with varying degrees of lifelong impairment across multiple sectors, thus warranting a variety of tailored and sustainable support systems [5]. While much of this paper addresses the mental health needs of a wide range of individuals with DD, special focus is placed on the lack of robust and accessible mental health services for individuals with ID.

Mental illness has greater prevalence in individuals with DD than the general population.

While statistics vary, it is known that mental illness has a greater prevalence in individuals with developmental disabilities (DD) compared to the rest of the population [6, 7, 8, 9]. An estimated 35 percent to 40 percent of those diagnosed with DD also have a diagnosed psychiatric disorder [6]. The comorbidity of DD and mental illness or behavioral difficulties such as aggression, depression, anxiety, and addiction is referred to as "dual diagnosis" for the purposes of this paper [7, 10, 11].

Although psychological disorders commonly occur alongside DD, these disorders are chronically underdiagnosed, misdiagnosed, or poorly managed [5, 12, 13]. Diagnostic overshadowing, in which symptoms of mental or physical illness are misinterpreted as symptoms of one's DD, is a likely contributor to suboptimal care which results in less likely diagnosis of psychiatric disorders in this group despite higher occurrence [13]. For example, individuals with DD are less likely to have developed coping skills and, as a result of potentially limited verbal skills, may resort to physical aggression in order to express their discomfort or stress [7]. Alternatively, physical aggression could be rooted in a mental illness or be an expression of pain resulting from a medical issue [7]. There are numerous explanations for this single behavior; however, clinicians are quick to assume the behavior is attributed to DD rather than exploring alternate causes as would be done for individuals without DD. Hence, the diagnosis of an DD can overshadow any other diagnosis. Without maintaining a high index of suspicion for alternate causes of their behavior, people with DD or mental health disorders are denied appropriate screenings, treatments, and investigations necessary for making alternate diagnoses and maintaining good health [13].

In short, the clinical presentations of psychiatric disorders for people also diagnosed with DD are not well understood and are often misinterpreted as symptoms of DD. Variable presentations of DD from person to person make diagnosis even more difficult, especially if one is nonverbal [7, 10]. Recently, a diagnostic manual specific to ID, the Diagnostic Manual-Intellectual Disability or DM-ID-2, was published by the National Association for Dual Diagnosis (NADD) in order to address the issue of diagnostic overshadowing and increase understanding of psychiatric disorders in context of ID [10].

Despite these advances, other challenges persist and mental health services available for people with DDs remain undefined and underdeveloped [5]. Furthermore, individuals with dual diagnosis often slip through existing cracks between non-overlapping areas of DD healthcare and behavioral or mental healthcare, assuming they are able to be accurately diagnosed with both disorders in the first place [10]. Thus, there is a major unaddressed need for mental health care that is both inclusive of and accessible to people with DD.

A dual diagnosis of DD and a psychiatric disorder increases the risk of abuse.

Although societal biases would lead some people to believe that those with DD are either worry free or exempt from emotional stress due to a general inability to express their feelings, statistics regarding individuals with dual diagnosis show otherwise [12]. While they may struggle to communicate a traumatic experience, children with DD are significantly more likely to experience traumas including adverse childhood events, bullying, abuse, seclusion, domestic violence, restraints, and more compared to children without DD [10]. Spectrum Institute has several publications on this topic. [32]

People with disabilities, especially DDs, have also been historically more vulnerable to crime [14]. These emotional stressors can lead to an even greater need for mental health services which remain inaccessible to people with DD and psychiatric disorders. The impact of these traumas, especially those caused by seemingly trivial events,

on individuals with DD can be discounted by service providers [10]. Likewise, crimes committed against people with disabilities are likely to go unreported, to be described as "incidents" rather than crime, and unprosecuted because of "unreliable" testimony from a person with DD [14]. Still, the trauma that results from victimization of people with DD and/or psychiatric disorders requires the help of mental health professionals, few of which have the training to account for disabled people in their practice [14].

Mental health services for individuals with dual diagnosis fall short.

Adequate healthcare is necessary to enhance quality of life and allot individuals to pursue their interests and desired activities [6], yet health care for the dually diagnosed often falls short.

One study suggests that people with both DD and a mental health disorder have higher unmet treatment needs in terms of adaptive skills and cognitive needs [15]. These unmet needs include a lesser understanding of one's own health conditions resulting in reduced compliance with medical treatments, lack of transportation impeding access to health care and socialization, and others [15]. These factors can all accumulate to exacerbate one's DD or mental illness, having a negative overall impact on one's health.

Furthermore, given the importance of early identification of disability and implementation of therapy for positive long-term outcomes for people with DD [3], the lack of clarity in terms of effective treatments is astonishing. For example, differing conclusions have been drawn about the efficacy of specialized mental health services in comparison to general mental health services [16]. General mental health services are thought to avoid segregation and discrimination but could require working with less knowledgeable and understanding providers [16]. On the other hand, specialized mental health services are thought to better meet the needs of the DD community but can feel stigmatized and may be less affordable [16]. While any clinician can take on a client with DD and mental illness, additional certifications offered by organizations like NADD to better tailor treatment to the individual's diagnoses and ensure competency of the clinician should be more widely used [17].

Similarly, the genre of therapy which is most effective is also debated. Reports investigating the efficacy of psychotherapy for people with ID are conflicting, with some saying the effect is significant and others disagreeing often depending on the severity of ID [5]. Cognitive-behavioral therapy is another approach which is generally considered to be a promising effective treatment for individuals with ID [5]. Whatever the psychotherapeutic intervention, several improvements are recommended to better cater to people with ID including the use of visuals, repetition, involving caregivers, working in small increments with breaks, and reducing abstract language [5, 18].

Overall, the preferred method of treatment for individuals with dual diagnosis tends to vary by individual, by psychologist and/or physician, and with time. Our understanding of which treatments work best is constantly evolving along with our understanding of dual diagnosis itself, which can complicate treatment.

Additional barriers impact access to available mental health services for people with dual diagnosis. Multiple studies support the idea that dually diagnosed people are poorly supported by existing health care services across the globe [15, 19]. While many people may have difficulties accessing health care, there are additional barriers for people with DD which can be life threatening [20]. In the past, the health of people with DD has been poorly tracked and researched through national surveys; however, the recent inclusion of disability items on platforms such as the Behavioral Risk Factor Surveillance have opened up the field and exposed inequities in health care [21, 22].

The 2001 *Report of the Surgeon General's Conference* on health disparities for people with ID admits that people with ID experience excessive "difficulty in finding, getting to, and paying for appropriate health care" compared to other populations due to an inaccessible system and biased providers [19]. These challenges are more pronounced for people with an ID who also identify with minority communities and therefore experience additional language and cultural barriers [19]. In general, people with all kinds of disabilities have historically experienced poorer access to health care as well as lesser quality health care compared to their non-disabled equivalents [21].

The culmination of several factors leads individuals who have a dual diagnosis of ID and a mental health disorder to be particularly barred from rapidly accessing adequate health care services. Some of the most prominent causes of this phenomenon are expanded upon below.

Insurance and lack of integrated health care settings impacts access to services. Many adults and children with DD live in poverty and therefore rely upon government-funded health care insurance [19]. Mental health services are less likely to be covered by insurance plans and often involve higher copays as well as limited services [23]. For this reason, people with DD who may already face expensive bills for any treatment they may be receiving for their DD can be deterred from mental health care services which would treat their mental health conditions.

In addition, treatment is often driven by diagnosis rather than symptoms, which can neglect the needs of some patients [11]. Given the phenomenon of diagnostic overshadowing, it can be difficult for an individual with DD to be formally diagnosed with a mental health disorder, which prevents them from accessing any treatment for that disorder under their insurance given that the diagnosis does not exist on paper despite the person exhibiting symptoms.

Furthermore, separate funding and regulation of physical and mental health facilities results in access to each system being determined solely by diagnosis rather than the presentation and health care goals of the patient [6]. Each diagnosis is assigned its own system and the health care provider will only be reimbursed for treating their assigned diagnosis, not any comorbid conditions [6]. For example, primary care physicians listing

treatment of a mental health diagnosis will not receive reimbursement [6]. Therefore, individuals with DD who also experience comorbid psychiatric disorders are forced to navigate several systems of care rather than one integrated healthcare plan [6].

Reimbursements for mental health services can become further complicated when using Medicaid, accessing preventative mental health services, or utilizing alternative practitioners or non-clinicians [24]. Insurance complications can incentivize people to neglect their health rather than use these services, despite their proven benefits. On the other hand, health care providers do not have incentives to ensure the health of people with DD or to accept government-funded insurance [19, 20]. This "demarcation between mental health and disability services" is one of the most prominent barriers to adequate and accessible healthcare for the dually diagnosed [16].

Integrated care is problematic. Integrated health care which involves coordination between primary health care clinicians with mental health services has proven benefits which can uniquely serve the DD community [6]. Considering the vast network of caretakers that individuals with DD may interact with — including social workers, healthcare providers, and educators — coordination of care is key to efficiency and has been shown to have real benefits [6, 24]. However, integrated care is impeded by caretakers who do not understand the interplay between physical health and mental health for individuals with DD [6]. While a large interdisciplinary team of caretakers play a role in an individual's healthcare, poor integration can result in redundancy, miscommunication, and diffusion of responsibility [16, 24]. Also, as previously discussed, this form of health care has been essentially dismissed as a feasible alternative due to excessive regulation from insurance companies which prevents patients from integrating their health care.

Other forms of treatment such as community-based settings also show better outcomes than current default treatments for people with DD [8]. Organizational supports within community-based settings are often supportive of mental and behavioral needs and in turn increase the participation of people with dual diagnosis in their community and positively impact their health [8]. However, current treatments for people with DD still recommend isolation and sometimes institutionalization upon diagnosis.

Overall, new treatment concepts for individuals with DD such as integrated healthcare plans and community-based services have improved upon traditional methods. [33] Yet, no transitions are being made toward superior forms of health care for people with DD and psychiatric disorders despite the opportunity they present to increase efficiency, reduce costs, and limit disparities [8]. This is likely due to the non-ubiquitous and subjective implementation of therapies which makes it difficult to determine effective treatments for the DD population, as discussed previously.

There is a lack of qualified providers. The need for specialized health services for people with DD was recognized in 1962 through the authorization of the Developmental Disability Act [22]. Yet, experts agree that today the increased prevalence of mental health

problems among individuals with DD is still juxtaposed by a lack of services to meet this need [5, 9, 19].

Medical professionals trained in both DD and mental illness are a rarity [12, 16], which promotes the occurrence of diagnostic overshadowing. Without the ability to accurately assess the physical and mental health of a person with dual diagnosis, clinicians deny these patients their right to competent medical assessment and treatment. Adequate training on how physical or mental illness can present in an individual with other DD diagnoses could prevent this from happening in the future [7].

Disability-focused training for health care providers has been recommended by some to improve health care services for people with DD [21]. Given the high risk of comorbidity for people with DD, some researchers posit that care providers should be educated on risks [25]. For example, substance related and addictive disorders (SRAD) are a common comorbidity for DD [25]. Thus, DD care providers should be aware of the potential for their patients to be experiencing addiction and thus be prepared with resources for addiction-focused services for people with DD, if they are not trained to treat addiction for individuals with DD themselves [25]. Likewise, SRAD care providers should be aware of how DD may influence a client's addiction and also have resources for people experiencing both DD and SRAD if they do not already possess the training to approach the topic of addiction in an DD-informed manner [25].

Geography, logistical barriers, and access to qualified professionals impact access to mental health services. Travel, distance, and location are considered general barriers to all healthcare services and are not specific to ID or mental health [9]. However, mental health professionals who specialize in DD and mental health are limited in number, aggravating the issue [5]. Since qualified professionals are more rare, it follows that they are more spread out geographically and even more difficult to travel to, especially when one's disability can complicate travel. Regardless, given the small number of specialists available, receiving treatment from adequately trained professionals may be too expensive for individuals with dual diagnosis who are more likely to come from low-resource backgrounds [15, 23].

Notably, recent tele-psychiatry methods such as remote videoconferencing are making health care more accessible [9]. Given the transition to completely remote activities that was made during the peak of the COVID-19 epidemic, it is safe to assume that available tele-psychiatry services have recently increased allowing more people to access healthcare services. While telehealth does present an opportunity for increased accessibility, it also presents a challenge for engaging patients.

Discrimination, stigmatization & negative expectations impact treatment outcomes. It's no secret that those diagnosed with DD face stigma in everyday life, a fact that was acknowledged in 2006 by The United Nations Convention on the Rights of Persons with Disabilities [18, 19]. People who are dually diagnosed can experience double stigmas meaning they are subjected to stereotypes from both of their disabilities [5].

Often, this can look like health care professionals being dismissive, unsupportive, and invalidating towards their client's experiences [5].

A health care professional's internalized stigma can seep into the clinical environment especially when they lack education and training related to DD [18]. Ableism, or the idea that those with disabilities are inferior and lack self-determination or self-advocacy, is one form of discrimination which can be exhibited by mental health professionals making clinical environments feel unsafe for people with DD [5]. This can lead to individuals with DD having poor experiences while seeking mental health services and, therefore, is a contributing factor to inadequate and inaccessible health care for this population [5, 19]. Furthermore, this discrimination can exclude people with DD from being educated about their own health care - preventing them from being self-advocates, potentially discouraging them from self-reporting symptoms, and exacerbating misunderstandings about DD [20]. Therefore, even when services are available, they may not be utilized [5].

Stigma and discrimination can severely limit the number of available, suitable, and willing mental health professionals who will accept clients dually diagnosed with DD [18]. As a result, people with both mental illnesses and DD are challenged to seek out specialty physicians given that awareness of DD is so limited in the field of mental health care [18]. Rather than harboring negative attitudes and stereotypes towards clients with DD, mental health professionals should work to address their internalized stigmas and validate their client's individual experiences and identity related to DD [18].

The consequences of denied mental health care on individuals with DD are both general and unique. General poor outcomes which result from people with DD being neglected by health care systems include higher morbidity rates and increased incidence of comorbidities, [20]. Studies have shown that treatment for mental health disorders can be delayed years after onset for any individual presenting with a psychiatric disorder, which can in turn result in increased mortality and morbidity such as substance abuse and suicide attempts [23]. These negative implications of delayed mental health care also apply to those who are also diagnosed with DD along with other ramifications which are unique to dual diagnosis.

There are economic burdens when services are denied or delayed. People who are diagnosed with both DD and a mental health disorder impact the economy, whether that be in the form of government assistance or institutionalization.

Mental health conditions are negatively correlated with education, employment, and income [23]. In turn, low levels of education and low income are positively correlated with a lack of health insurance [23]. Studies have shown that individuals with comorbid mental health disorders and DD are even less likely to reach higher levels of education and more likely to be receiving government aid [15].

Some of these factors, such as unemployment, then become involved in positive feedback cycles in which one's unemployment — which is likely a result of one's mental health

disorder or DD — further contributes to psychological distress which exacerbates their disability and prevents employment in the future [26]. Therefore. unemployment is both a consequence and determinant of mental health disorders [26]. The same idea could be applied to low income in that a lack of money prevents people from treating their disabilities, which can exacerbate their health, rendering them unable to make more money. This kind of catch-22 prevents people from improving their socioeconomic status and improving their health in multiple ways.

Economic burdens can also include institutionalization and incarceration. Additional economic implications are posed by people with both DD and a psychiatric disorder in that they are more likely to use emergency departments, hospitalizations, and readmissions [15]. This places a burden on first-responder and health care institutions, both of which receive compensation from the government increasing the economic burden posed by untreated DD and mental health disorders.

Another form of institutionalization that has a disproportionate representation of people with DD is the carceral system. Some data suggests that individuals with SRAD and DD are more vulnerable to incarceration [27]. Recently, 70% of the people on the National Registry of Exonerations claimed to have a mental illness or DD [28]. The carceral system costs the government billions of dollars [29] while over-representing, provoking, and creating disabilities. Without providing appropriate mental health and disability-focused health care, disabled people will continue to be forced into cycles which result in more harm rather than healing.

Substance-related and addictive disorders (SRAD) have significant adverse consequences. Current health care systems are ill equipped to provide for individuals who are mentally ill or have DD, and particularly ill equipped to assist individuals diagnosed with both disorders simultaneously. As a result, some individuals with dual diagnoses may resort to other sources of relief such as SRAD.

One study suggests that individuals with DD have a higher prevalence of SRAD [25, 27]. Furthermore, the majority of individuals with DD and SRAD also had a psychiatric comorbidity and were often more likely to be diagnosed with a chronic disease [25, 27]. This makes sense given that the association between mental health problems and SRAD is well defined [27].

Individuals with DD and SRAD are less likely to receive treatment and more likely to remain in treatment for longer periods of time [27], suggesting that treatments are not as effective for this population. Lack of research regarding the DD community and SRAD makes treatment risky for these individuals and could result in increased behavioral difficulties, physical difficulties, and adverse side effects to medical cocktails [27]. In short, the inability to treat DD and mental health disorders together can frequently lead to the development of other disorders — such as SRAD —which similarly has no solutions tailored to dually diagnosed communities.

Dual diagnosis impacts quality of life, relationships, independence, and social Interaction. Dual diagnosis has been found not only to influence educational opportunities, job prospects, and one's physical health but also social relationships [11, 27].

One study found that adults with DD are seven times more likely to report inadequate emotional support in comparison to adults without disabilities due to isolation [22]. More recent studies found adults with DD are 4.4 times more likely to receive inadequate emotional support [21]. This meant that adults with DD had no one to talk to about personal subjects, often felt lonely, and experienced barriers to spending time with friends [22]. Lack of caring for emotional health has been proven to put one's physical health at risk [22]. Thus, people with disabilities who may already be experiencing declining health may also have declining mental health due to a lack of emotional support, which in turn continues to worsen their disability.

On top of already poor health care for people with DD, which has been demonstrated through their lack of access to certain healthcare services and increased incidences of chronic health conditions, people with DD face barriers to caring for their emotional health which can have a detrimental impact on physical health and quality of life [21, 22].

Thus, there is not only an increased need for health care in the face of decreased access to services but also a need to re-imagine emotional support systems for dually diagnosed individuals [21].

A variety of untreated mental illnesses can lead to patients being a danger to themselves and a danger to others [30]. Lack of treatment for acute medical illness has also been linked to increased systemic costs as well as refractory mental illness with poor long-term prognosis [30]. Individuals with DD have a greater prevalence of mental illness and a greater prevalence of other disorders such as SRAD that put them at risk for poor prognosis and self-endangerment.

Most individuals with DD have similar causes of death to the general population; however, they die much earlier at an average age of 63.3 years for males and 69.9 years for females [6]. Whether this trend can be attributed to lack of emotional support, inadequate treatment of disorders, or other offenses of the health care system against people with dual diagnosis, the premature deaths of people with DD is alarming.

Conclusion

One's legal right to their own health with no distinction between social, religious, political, or economic denominations has been emphatically reaffirmed in constitutions and human rights declarations by the foremost government agencies [19, 24]- agencies which continue to fail the DD community.

The American Association on Intellectual and Developmental Disabilities (AAIDD) put it best when they declared: "all people, including people with DD, should have timely

access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs, maximizes health, well-being and function, and increases independence and community participation" [31]. The AAIDD, NADD, Arc of the United States and numerous other disability rights organizations have consistently advocated for this principle and yet little attention is paid to delayed and denied mental health treatment for individuals diagnosed with DD [10, 17, 19, 31]. The barriers outlined in this paper make it clear that people with DD struggle to obtain mental health services and are having their rights violated in the process. The resulting consequences not only shorten the lives of those directly affected but also have systemic, negative impacts on all of society.

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Emmi Deckard is a student at UCLA where she is majoring in bioengineering and minoring in disability studies. She wrote this paper while she was doing an internship with Spectrum Institute. She also wrote feature stories for the organization's website and helped produce episodes of The Freedom Files *podcast.*

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Note: This source was used to approximate the number of adults with DD in the U.S.

[2] Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009–2017. *Pediatrics*, *144*(4), e20190811. https://doi.org/10.1542/peds.2019-0811
Note: This source was used to outline the prevalence of DD in children. The study also explores categories of DD and associations with gender, ethnicity, education, and more.

[3] Durkin, M. S. (2019). Increasing Prevalence of Developmental Disabilities Among Children in the US: A Sign of Progress? *Pediatrics*, *144*(4). https://doi.org/10.1542/peds.2019-2005
Note: This source was used to deduce general trends in DD including reasons behind increasing rates of DD.

[4] *Facts about Developmental Disabilities | NCBDDD | CDC*. (2019, September 26). Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html
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[5] Campbell, J., & Scarpa, A. (2019). Psychotherapy For Developmental Disabilities. *Oxford Clinical Psychology*. Published. https://doi.org/10.1093/med-psych/9780190912727.003.0014
Note: This source was used to explain the diversity of people with dual diagnosis and the healthcare system's failure to adequately treat their disorders.

[6] Ervin, D. A., Williams, A., & Merrick, J. (2014). Primary Care: Mental and Behavioral Health and Persons with Intellectual and Developmental Disabilities. *Frontiers in Public Health*, *2*. https://doi.org/10.3389/fpubh.2014.00076
Note: Ervin et al. discuss how integrated healthcare can uniquely benefit people with DD and barriers in receiving higher quality care. Ervin et al. also explain the pros and cons to an integrated healthcare system for individuals with DD.

[7] Tang, B., Byrne, C., Friedlander, R., McKibbin, D., Riley, M., & Thibeault, A. (2008). The Other Dual Diagnosis: Developmental Disability and Mental Health Disorders. *BC Medical Journal, 50*(6), 319-324. https://bcmj.org/articles/other-dual-diagnosis-developmental-disability-and-mental-health-disorders
Note: Tang et al. discuss how behaviors of people with DD and mental health issues can be misinterpreted, leading them to receive less healthcare attention. Tang et al. also discuss the infrastructure of healthcare for individuals with DD in British Colombia.

[8] Friedman, C. (2019). Organizational Supports to Promote the Community Integration of People With Dual Diagnosis. *Intellectual and Developmental Disabilities*, *59*(2), 101–111. https://doi.org/10.1352/1934-9556-59.2.101
Note: This source explains new treatment ideas for people with DD and psychiatric disorders - mainly the use of community-based treatments and supports.

[9] Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2017). Barriers and Enablers to Accessing Mental Health Services for People With Intellectual Disability: A Scoping Review. Journal of Mental Health Research in Intellectual Disabilities, 11(1), 69–102 https://doi.org/10.1080/19315864.2017.1408724
Note: This source discusses barriers and enablers to accessing mental health services for people with ID.

[10] Constantino, J. N., Strom, S., Bunis, M., Nadler, C., Rodgers, T., LePage, J., Cahalan, C., Stockreef, A., Evans, L., Jones, R., & Wilson, A. (2020b). Toward Actionable Practice Parameters for "Dual Diagnosis": Principles of Assessment and Management for Co-Occurring Psychiatric and Intellectual/Developmental Disability. *Current Psychiatry Reports*, *22*(2). https://doi.org/10.1007/s11920-020-1127-8
Note: This source better explains the issue of dual diagnosis.

[11] Ervin, D. A., Williams, A., & Merrick, J. (2015). Adults, mental illness and disability. *International Journal on Disability and Human Development*, *14*(2). https://doi.org/10.1515/ijdhd-2015-0005
Note: This source clarifies a need for integrative medical care.

[12] Gentile, J. P. & Jackson C. S. (2008). Supportive Psychotherapy with the Dual Diagnosis Patient: Co-occurring Mental Illness/Intellectual Disabilities. *Psychiatry, 5*(3), 49-57. https://pubmed.ncbi.nlm.nih.gov/19727299/
Note: This source discusses future directions of therapy for individuals with dual diagnosis.

[13] Ali, A. & Hassiotis, A. (2008). Illness in people with intellectual disabilities. *BMJ*, *336*(7645). https://doi.org/10.1136/bmj.39524.514931.ad
Note: This source was used to define diagnostic overshadowing and its implications.

[14] Petersilia, J. R. (2001). Crime Victims with Developmental Disabilities. *Criminal Justice and Behavior*, *28*(6), 655–694. https://doi.org/10.1177/009385480102800601
Note: This source explains how people with disabilities are disproportionately targets for crime and acts of violence.

[15] Durbin, A., Sirotich, F., Lunsky, Y., & Durbin, J. (2015). Unmet Needs of Adults in Community Mental Health Care With and Without Intellectual and Developmental Disabilities: A Cross-Sectional Study. *Community Mental Health Journal*, *53*(1), 15–26. https://doi.org/10.1007/s10597-015-9961-6
Note: This study explains how unmet needs of people with dual diagnosis differ from those of people with just mental health diagnoses.

[16] Monash University, Sullivan, D., Robertson, T., Daffern, & M., Thomas, S. (2013, October). *Building capacity to assist adult dual disability clients access effective mental health services*. https://doi.org/10.13140/2.1.3882.4642
Note: Sullivan et al. discuss different treatment models including generalized vs. specialized mental health services for populations with ID.

[17] Edelberg, J. C., PhD. (2021, March 29). *Psychotherapy for clients with Intellectual Disabilities: Progress and Adaptations for Effectiveness*. Maine Psychological Association. Retrieved December 14, 2021, from https://mepa.org/psychotherapy-for-clients-with-intellectual-disabilities-progress-and-adaptations-for-effectiveness/
Note: This source was used to reference NADD training programs for psychologists.

[18] Ditchman, N., Werner, S., Kosyluk, K., Jones, N., Elg, B., & Corrigan, P. W. (2013). Stigma and intellectual disability: Potential application of mental illness research. *Rehabilitation Psychology*, *58*(2), 206–216. https://doi.org/10.1037/a0032466
Note: This source was used to expand on the stigmatization of ID in mental healthcare.

[19] U.S. Public Health Service. Closing the Gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. February 2001. Washington, D.C. https://www.ncbi.nlm.nih.gov/books/NBK44346/
Note: This source describes the national conference held to address health care accessibility for people with ID (formerly referred to as mental retardation).

[20] Ervin, D. A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for Persons with Intellectual and Developmental Disability in the Community. *Frontiers in Public Health*, *2*. https://doi.org/10.3389/fpubh.2014.00083
Note: Similarly to this paper, Ervin et al. discuss discrimination against people with DD and the poor outcomes which can result. This paper was used for general background relating to this history of people with DD and healthcare.

[21] Havercamp, S. M., & Scott, H. M. (2015). National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal*, *8*(2), 165–172. https://doi.org/10.1016/j.dhjo.2014.11.002
Note: Havercamp et al. outline inequitable access to healthcare using statistics derived from a national survey.

[22] Havercamp, S. M., Scandlin, D., & Roth, M. (2004). Health Disparities among Adults with Developmental Disabilities, Adults with other Disabilities, and Adults Not Reporting Disability in North Carolina. *Public Health Reports*, *119*(4), 418–426. https://journals.sagepub.com/doi/pdf/10.1016/j.phr.2004.05.006
Note: This study elucidates barriers that people with DD face when accessing primary health care as well as emotional support systems, both of which can negatively impact mental health.

[23] Mclaughlin, C. G. (2004). Delays in Treatment for Mental Disorders and Health Insurance Coverage. *Health Services Research*, *39*(2), 221–224. https://doi.org/10.1111/j.1475-6773.2004.00224.x
Note: This source was used to elucidate the negative impact that delayed treatment can have on any individual with a mental disorder.

[24] Office of the United Nations High Commissioner for Human Rights & World Health Organization. (2008, June). *The Right to Health*. https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf
Note: This source discusses one's legal right to healthcare as defined by global leadership organizations.

[25] Lin E, Balogh R, McGarry C, et al. Substance- related and addictive disorders among adults with intellectual and developmental disabilities (IDD): an Ontario population cohort study. BMJ Open 2016;6:e011638. doi:10.1136/bmjopen-2016- 011638
Note: This source discusses substance abuse and addiction among adults with DD.

[26] Olesen, S. C., Butterworth, P., Leach, L. S., Kelaher, M., & Pirkis, J. (2013). Mental health affects future employment as job loss affects mental health: findings from a longitudinal population study. *BMC Psychiatry*, *13*(1). https://doi.org/10.1186/1471-244x-13-144
Note: This source discusses relationships between mental health and unemployment.

[27] Carroll Chapman, S. L., & Wu, L. T. (2012). Substance abuse among individuals with intellectual disabilities. *Research in Developmental Disabilities*, *33*(4), 1147–1156. https://doi.org/10.1016/j.ridd.2012.02.009
Note: This source clarifies the consequences of SRAD that occur with DD.

[28] University of Michigan Law. (2020). AGE AND MENTAL STATUS OF EXONERATED DEFENDANTS WHO CONFESSED. https://disabilityandguardianship.org/age-and-mental-status.pdf
Note: This source provides statistics related to how many individuals who have been exonerated declared a mental health or DD diagnosis.

[29] Carroll, Heather. (2016). "Serious Mental Illness Prevalence in Jails and Prisons." *Treatment Advocacy Center*. https://www.treatmentadvocacycenter.org/component/content/article/220-learn-more-about/3695-serious-mental-illness-prevalence-in-jails-and-prisons-
Note: This source was used to estimate the cost of the carceral system to the government and to explain the prevalence of mental illness in prisons and jails.

[30] Biswas, J., Drogin, E. Y., & Gutheil, T.G. (2018). Treatment Delayed is Treatment Denied. *The Journal of the American Academy of Psychiatry and the Law, 46*(4), 447-453. http://jaapl.org/content/46/4/447

Note: This source describes the clinical implication of delayed treatment or untreated mental illness.

[31] *Health Mental Health Vision and Dental Care*. (2013). American Association on Intellectual and Developmental Disabilities (AAIDD). Retrieved December 14, 2021, from
Note: This source is one example of the stance that disability advocacy organizations take regarding healthcare access for people with DD.

[32] To read more about people with disabilities being abused at higher rates, see the following publications of Spectrum Institute:

Baladerian, N. J., Coleman, T. F., & Stream, J. (2013). *Abuse of People with Disabilities: Victims and Their Families Speak Out*. Spectrum Institute. https://tomcoleman.us/publications/2013-survey-report.pdf
Note: This source discusses statistics regarding the physical, sexual, and emotional abuse of people with DD as informed by a national survey. It also proposes solutions to address this issue.

Coleman, T. F. *A Review of the Association Between Childhood Disability and Maltreatment.* Spectrum Institute. https://tomcoleman.us/publications/child-maltreatment-synopsis.pdf
Note: This source discusses abuse, maltreatment, and neglect experienced by people with various disabilities, mostly children, citing numerous studies which speak to the prevalence of this issue.

Coleman, T. F. (2019). *Disability and Abuse: Evidence-Based Data Should Drive the Narrative.* Spectrum Institute. https://tomcoleman.us/publications/evidence-based-data.pdf
Note: This source builds on the previous commentary and calls into question existing statistics regarding the prevalence of disability and abuse while demanding more robust and more recent data.

[33] To read more about existing and developing treatments for adults and children with DD who have experienced trauma or who experience various mental health conditions which may be treated with mental health therapy, see the following two-part bibliography created by Spectrum Institute.

Coleman, T. F. *Intellectual and Developmental Disabilities: A Bibliography on Trauma and Therapy, Part One: Books.* Spectrum Institute. https://spectruminstitute.org/wp-content/uploads/2021/02/bibliography-books.pdf

Coleman, T. F. *Intellectual and Developmental Disabilities: A Bibliography on Trauma and Therapy, Part Two: Articles and Other Resources.* Spectrum Institute. https://spectruminstitute.org/wp-content/uploads/2021/02/bibliography-part-2.pdf

The Mental Health Project

Purpose. The purpose of the Mental Health Project of Spectrum Institute is to promote improved access to a full range of mental health therapies for adults with intellectual and developmental disabilities.

Focus. The project focuses on the role of guardians, conservators, and others who have assumed primary caregiving responsibilities for this special needs population. These individuals are mental health therapy fiduciaries.

Mission. The mission of the project is to educate these fiduciaries about their duty to take the necessary steps to implement the right of adults with intellectual and developmental disabilities to have prompt access to the necessary and appropriate mental health therapies they need. The mission also includes the education of self advocates and family advocates on the right to mental health therapy and how to ensure that court-appointed agents and those who have assumed caregiving responsibilities fulfill their fiduciary duties.

Methods. The project accomplishes its mission through research, education, and advocacy. In addition to working with advocates and mental health fiduciaries, it also reaches out to primary care physicians who are often the gatekeepers to mental health services, and to psychologists, psychiatrists, social workers, and other licensed mental health professionals.

https://spectruminstitute.org/mental-health-project/

Mental Health Therapy is a Legal Right for People with Intellectual and Developmental Disabilities

A National Civil Rights Declaration

The constitution protects the right of adults to make their own medical decisions. (*Cruzon v. Missouri* (1990) 497 U.S. 261, 262; *Thor v. Superior Court* (1993) 5 Cal.4th 725, 731)

People with developmental disabilities have the right to full participation in society and to equal access to health care services. (ADA Section 12101; Wash. Rev. Codes Section 71A-10.030)

When courts give the power to make health care decisions to guardians or conservators, these fiduciaries must be pro-active. They must become aware of the need for and arrange for appropriate mental health treatment for adults under their care. (Los Angeles Daily Journal Commentary)

Many individuals with intellectual and developmental disabilities experience chronic trauma and may also have trauma-related medical conditions as a result of abuses they have experienced. They need trauma-informed therapy. Many also have a dual diagnosis due to mental health conditions arising from other causes. They need appropriate and effective mental health therapy. (Commentary: "Trauma-Informed Justice: A Necessary Paradigm Shift for the Limited Conservatorship System; Commentary: "Disability and Abuse: Evidence-Based Data Should Drive the Narrative")

There are a wide range of mental health therapy options available for people with intellectual and developmental disabilities, including therapies to treat trauma, depression, anxiety, and PTSD. ("Intellectual and Developmental Disabilities: A Bibliography on Trauma and Therapy" [Part One: Books] [Part Two: Articles and Other Resources])

Individuals with intellectual and developmental disabilities have a right to prompt medical care and treatment. (Cal. Welf. & Instit. Code Section 4502(b)(4)) Failure to provide such care is neglect.

Additional qualified professionals are needed to provide therapy for individuals with intellectual and developmental disabilities. Those already working in this field, such as the 450 therapists approved by regional centers in California, should improve their skills with in-service training. (Vendor Lists of Regional Centers) Trauma-informed therapy should be included in all training programs.

Care providers who deprive necessary health care services to dependent adults in their custody or care commit dependent adult abuse. (Wash. Rev. Codes Section 74.34.020(16)) Medical care includes mental health therapy. Deliberate indifference to medical and mental health needs is unconstitutional. (*Doty v. County of Larsen* (9th Cir. 1994) 37 F.3d 540, 546)

People without disabilities have access to a full range of mental health therapies. It is disability discrimination for guardians, conservators, or other care providers to deprive individuals with disabilities access to a full range of mental health therapy options. (*Federal Law:* Americans with Disabilities Act; *State Law:* Cal. Gov. Code Section 11135; Wash. Rev. Codes Section 49.60.030)

Endorsed by: Arc of California, California Siblings Leadership Network, Autistic Self Advocacy Network, TASH, Washington Autism Alliance and Advocacy, Disability Rights Legal Center, Mental Health Advocacy Services, Barrier Free Living, Louisiana State Nurses Association, and West Virginia Developmental Disabilities Council.

To be listed as an endorser, contact Spectrum Institute at: tomcoleman@spectruminstitute.org.
The declaration is available online at: https://spectruminstitute.org/declaration.pdf

Endorsing Organizations

The following organizations have endorsed the **Legal Principles** underlying the right of people with developmental disabilities to have prompt and equal access to a full range of mental health therapies that are available to people without development disabilities.

Mental Health Advocacy Services, Inc. (MHAS) is a private, non-profit organization established in 1977 to provide free legal services to people with mental disabilities.

The **Autistic Self Advocacy Network** seeks to advance the principles of the disability rights movement with regard to autism.

Different Brains® strives to encourage understanding & acceptance of individuals who have variations in brain function and social behaviors known as neurodiversity.

The **NDRN** is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for individuals with disabilities.

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

The **Louisiana State Nurses Association** website is the hub for information, resources, events, and member benefits. From professional development to health policy, our goal is to serve all professional nurses.

Founded in 1975, **Disability Rights Legal Center** (DRLC) is a 501C-3 non-profit, public interest advocacy organization that champions the civil rights of people with disabilities as well as those affected by cancer.

To partner with **California Sibs** (siblings of individuals with disabilities) in finding and creating information, community, and tools to promote with their brothers and sisters the issues important to them and their entire families.

TASH is an international leader in disability advocacy advocating for human rights and inclusion for people with significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization.

Washington Autism Alliance (WAA) extends access to healthcare, education and services for people with autism spectrum disorders (ASD's) & related intellectual and developmental disabilities (IDD) in Washington State.

Biographies

Thomas F. Coleman has been advocating for the rights of people with disabilities since 1980 when he was executive director of the Governor's Commission on Personal Privacy in California. The commission focused on a wide range of disability issues.

From 1984 to 1989 Coleman was a member of the Attorney General's Commission on Racial, Ethnic, Religious, and Minority Violence. Part of the commission's attention dealt with violence against people with disabilities.

From 1986 to 1988, Coleman was the principal consultant to the Los Angeles City Task Force on Family Diversity. He wrote its final report, which included a major chapter on Families with Members Who Have Disabilities.

In 2007, Coleman became legal director of a Disability and Abuse Project, which in 2012 conducted the largest national survey on abuse and disability. In 2013, Coleman was the primary author of a report on the findings and recommendations arising out of that survey. The report is titled: Abuse of People with Disabilities: Victims and Their Families Speak Out.

Coleman has also developed a comprehensive bibliography on books and articles on mental health therapies for people with developmental disabilities. He has published several articles on disability and child maltreatment, prevalence of abuse of people with disabilities, and the need for trauma-informed justice in guardianship and conservatorship proceedings.

In 2013, Coleman created a Disability and Guardianship Project under the auspices of Spectrum Institute, a nonprofit organization promoting guardianship and conservatorship reform, disability rights, and improved access to mental health services for adults with developmental disabilities. He is the author of a statement of legal principles underlying the right to such services. The principles have been endorsed by a wide range of advocacy organizations.

In 2016, Coleman and filmmaker Greg Byers produced a documentary film titled Pursuit of Justice. It tracks the efforts of Coleman and a team of advocates as they were promoting guardianship and conservatorship reform in California and throughout the nation.

Coleman has written many policy reports and commentaries on disability rights, supported decision-making as an alternative to guardianship, and targeted systemic reforms to conservatorship and guardianship systems. He has also made presentations on these issues at state, national, and international conferences.

Coleman has been practicing law since 1973.

Emmi Deckard is a senior at UCLA, majoring in bioengineering and minoring in disability studies. She was a feature story writer and an assistant producer for Spectrum Institute's podcast from April 2021 to December 2021. During this time, Emmi conducted multiple interviews with leaders in the disability rights movement, solicited conservatorship data from California's superior courts, increased Spectrum Institute's following through outreach, and ultimately played an integral role in the achievements of several of Spectrum Institute's projects.

Emmi's passion for disability rights stems from her experiences volunteering at a therapeutic equestrian center. She continues to pursue this passion today through advocacy, education, and partnership with organizations such as Momentum. Currently, Emmi is pursuing two research projects at UCLA – one the intersection of disability, incarceration, and access to health care with Dr. Laura Abrams and another regarding pediatric epilepsy treatment and diagnosis with Dr. Shaun Hussain.

Emmi is co-director of *Alternative Breaks UCLA*, a service club which encourages the formation of active citizens through education, service, and reflection on numerous social justice issues. She was previously a reporter at the *Daily Bruin*, UCLA's award-winning newspaper, from 2018-2021. In the future, she hopes to be accepted into medical school as a candidate in the 2022-2023 application cycle. As a health care provider, Emmi would like to focus on advocating for patients, especially those with disabilities, and increasing access to health care for minorities.

Christina Baldwin graduated from University of California, Berkeley in Geography and Washington State University in Food Science and Human Nutrition. She finished the academic work for a Master's in Counseling Psychology. She became a registered dietitian but found personal and professional bliss teaching yoga and meditation. Starting in 2007, it became clear that her life up to this point was preparation for addressing events and eventually activities that brought her to Spectrum Institute and the Mental Health Project.

Tina is married and has one daughter.

Mental Health Project Advisors

Thomas Buckley, Ed.D. has an impressive curriculum vitae. For the past two years, he has been the Director of Population Health at YAI — a world class organization providing exceptional-quality, culturally competent, person-centered services and supports to over 20,000 persons with intellectual and developmental disabilities. Prior to that, Dr. Buckley was the CEO and founder of The Buckley Medical Home — operated by a collaborative transdisciplinary team offering a healthcare delivery approach focusing on the whole person with an Intellectual/Developmental Disability (I/DD) and/or mental health conditions including progressive dementia. He also serves on the board of directors of the Commission on Accreditation of Rehabilitative Facilities. CARF International is an independent nonprofit organization that has accredited over 57,000 agencies, certifying that they meet specialized standards of care for mental health.

Simone Ebbers MSc. is a healthcare psychologist, child psychologist, psychotraumatherapist and EMDR-practitioner. Simone has been working in secondary and higher vocational education. She also worked as a behaviour specialist within a treatment centre for children and teenagers with a mild intellectual disability and psychiatric issues. Since 2013 she runs a private practice assessing and treating trauma and sexual abuse, and specializes in working with people with intellectual disabilities. Next to the clinical work, Simone also works as an educator, trainer, supervisor and adviser. In 2002, she wrote a study book on sexuality and sexual abuse for care providing professions. She is also co-author of: Psychological First Aid for people with intellectual disabilities who have experienced sexual abuse.

Attorney Jenny Farrell has accepted our invitation to be an advisor to the Mental Health Project of Spectrum Institute. Having an attorney with experience in mental health law will be of great value to the project. Ms. Farrell serves as the Executive Director of Mental Health Advocacy Services (MHAS). MHAS has been a leader in the disability rights movement and specifically in the fight for equal rights for people with mental health disabilities for over forty years. Through a combination of direct services, impact litigation, policy advocacy, education, and technical assistance, MHAS advocates for the civil rights, full inclusion, and equality of adults and children with mental health disabilities. As Executive Director, Jenny is responsible for overseeing the administration, programs, and strategic plan of the organization. Jenny earned her B.A. degree in Government from Smith College and her J.D. degree from the University of Southern California Gould School of Law. She is licensed to practice law in the State of California.

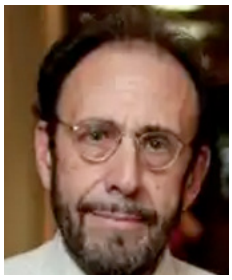
Virginia Focht-New is Associate Director Emeritus for the Clinical Services for Vulnerable Adults clinic at Widener University. She is a certified psychiatric clinical nurse specialist with an additional certification in biofeedback and with the NADD (an association for people with intellectual differences and mental health needs). Ginny is a recently retired Clinical Associate Professor and continues as an adjunct. She has been teaching social work students since 2006. In addition, Ginny has supported people with intellectual/developmental disabilities (ID) in several capacities for over 50 years. She has provided consultation in several states. Ginny has been a therapist for almost 30 years. She has also provided legal expertise, has made numerous presentations, and has publications in a variety of journals.

Reverend William C. Gaventa is the chair of the National Collaborative on Faith and Disability and Director of the Summer Institute on Theology and Disability. As writer and author, Rev. Gaventa served as Editor of the *Journal of Religion, Disability, and Health* from 1996-2010. He edited the newsletter for the Religion and Spirituality Division of the American Association on Intellectual and Developmental Disabilities, was an adviser for the Spiritual and Religious Supports Series for *Exceptional Parent Magazine*, and was a columnist for *Insight*, the national newsletter of the Arc USA. Rev. Gaventa is the author of *Disability and Spirituality: Recovering Wholeness* (Baylor University Press – 2018)

Dr. Matthew P. Janicki is co-chair of the National Task Grroup on Intellectual Disability and Dementia Practices. He is a member of the Federal Advisory Council on Alzheimer's Research, Care, and Services. Dr. Janicki is an associate professor in the Department of Disability and Human Development at the University of Chicago. He is also a research professor with the University of Maine's Center on Aging. Dr. Janicki is the author of many books and articles on aging, dementia, public policy, and rehabilitation of people with intellectual and developmental disabilities, including *Dementia, Aging, and Intellectual Disabilities: A Handbook.*

Marshall B. Kapp, J.D., M.P.H. (Colleges of Law & Medicine) was educated at Johns Hopkins University (B.A.), George Washington University Law School (J.D. with Honors), and Harvard University School of Public Health (M.P.H.). Now a Professor Emeritus, he was the Founding Director of the Florida State University Center for Innovative Collaboration in Medicine and Law from 2010 through 2017, with faculty appointments as Professor, Department of Geriatrics, FSU College of Medicine, and Professor of Medicine and Law in the FSU College of Law. He also was a Faculty Affiliate of the FSU Pepper Institute on Aging and Public Policy and the FSU Institute for Successful Longevity. He currently is an Adjunct Professor, Stetson University College of Law (teaching in the Elder Law LLM program) and an Adjunct Professor at the FSU College of Law (teaching in the Juris Masters program). Earlier, Kapp served as the Garwin Distinguished Professor of Law & Medicine at Southern Illinois University School of Law and School of Medicine and as Co-Director of the School of Law's Center for Health Law and Policy (2003-2009).

Biza Stenfert Kroese is a Consultant Clinical Psychologist and a Senior Researcher in the School of Psychology at the University of Birmingham, UK, and Chair of CanDo, a support service for parents with intellectual disabilities. Dr. Stenfert Kroese is co-author of *Cognitive Behaviour Therapy for People with Intellectual Disabilities: Thinking Creatively* (Palgrave Macmillan 2017). The book is based on the authors' clinical experiences and introduces novel approaches on how to adapt CBT assessment and treatment methods for individual therapy and group interventions. It explains the challenges of adapting CBT to the needs of clients with intellectual disabilities and suggests innovative and practical solutions.

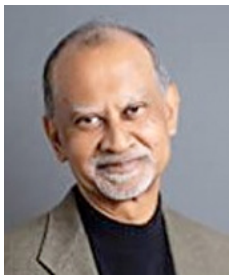


Gary LaVigna, Ph.D. is the Clinical Director of the Institute for Applied Behavior Analysis in Los Angeles. He spends much of his time consulting with organizations on establishing nonaversive behavior support plans for individuals exhibiting severe and challenging behaviors and presenting seminars on the topic throughout the world. Dr. LaVigna's work is reported in numerous articles and his coauthored books, such as *Alternatives to Punishment, Progress Without Punishment* and *The Periodic Service Review: A Total Quality Assurance System For Human Services and Education*. He is also coauthor of *New Directions in the Treatment of Aggressive Behavior for Persons with Mental and Developmental Disabilities*. (Nova Science Publishers, Ltd. 2015)

Daniel B. LeGoff. Ph.D., LS. is a licensed and board-certified pediatric neuropsychologist and the pioneer of LEGO® Therapy. He specializes in the assessment and treatment of neurodevelopmental and neurobehavioral conditions in infants, children, and adolescents. He is the author of *LEGO®-Based Therapy: How to build social competence through LEGO®-based Clubs for children with autism and related conditions* (Jessica Kingsley Publishers 2014). More recently, Dr. LeGoff wrote *How Lego-Based Therapy for Autism Works.* Through a series of case studies, the book explains how and why Lego therapy helps to promote the development of social skills for children with autism spectrum disorders (ASDs) and related conditions.

James A. Mulick, Ph.D. is a professor emeritus in the departments of pediatrics and psychology at Ohio State University and at Nationwide Children's Hospital. His research has focused on developmental and behavioral pediatrics, emphasizing the application of behavior analysis in the treatment of autism and other developmental disabilities. As a member of the Council of Representatives of the American Psychological Association, Dr. Mulick advocates for the right of individuals with developmental disabilities to effective treatment. Dr. Mulick is a recipient of a Lifetime Achievement Award from the Ohio Psychological Association, the John W. Jacobson Award for Critical Thinking from Div. 33, and the Karl F. Heiser APA Presidential Award for Advocacy. He has published in the scientific literature in his specialties and is an editor or co-editor of 16 books.

José R. Rosario is a speaker, author, and above all, an advocate. As a member of many diverse identity groups, José recognizes that common experiences bring people together and that taking stock of who we are gives us power. José wants to inspire others to acknowledge their identities, share their stories and empower those who are underrepresented to rise. As a mental health professional, José understands that this empowerment, and the creation of a space to be vulnerable, can lead to individual and group growth, awakening agents for change. José is a Clinical Psychology Ph.D. student at Clark University studying the factors associated with collective trauma and healing within silenced communities. From this passion, José launched The Phoenix Empowered, an organization focused on mental health disparities in minoritized groups. In addition, he is an Expressive Arts Facilitator through the PeaceLove Studios.



Nirbhay N. Singh, Ph.D., FAPA, FAPS, BCBA-D, is a Clinical Professor of Psychiatry and Health Behavior at the Medical College of Georgia at Augusta University. He is also the CEO of MacTavish Behavioral Health LLC, an agency devoted to training, research and consultation focused on people who are disabled or disenfranchised. He is the author of 750 publications, including 26 books. For about 30 years, Dr. Singh was an expert consultant in psychology, psychopharmacology, protection from harm, special education and mental health with regard to the care of people with disabilities for the Civil Rights Division of the Department of Justice (DOJ) in Washington, DC. The DOJ investigates violations of the Civil Rights of Institutionalized Persons Act.

Acknowledgments

Thomas F. Coleman

Just when I thought that Spectrum Institute's plate was full, Tina Baldwin suggested we create a Mental Health Project. She cited anecdotal evidence and research studies showing that adults with developmental disabilities were not receiving equal access to mental health services. I knew from my own prior work with abuse and disability that disabled victims of abuse were generally not receiving therapy to help them cope with and work through the trauma and other adverse effects. I also knew that while therapies for this population were available, access to effective mental health services was hindered by an insufficient number of qualified therapists.

I agreed with Tina that we should address this issue in the form of a project. So, Tina and I developed a mission statement, I drafted a statement of legal principles and lined up organizations to endorse them, Tina enlisted a panel of professional advisors, and we invited college students to participate as interns.

Then Emmi Deckard appeared. An intelligent and inquisitive UCLA undergraduate student, Emmi agreed to tackle our first project. We asked her to investigate and write a research paper on the consequences to adults with developmental disabilities when needed mental health services are delayed or denied. Emmi dug right in and in a matter of a few months she produced a masterful paper on this topic.

After Tina and I did some editing, Emmi finalized the paper and we submitted it to our panel of professional advisors for review and comment. The remarks of some of them are contained in this report.

I am grateful to Tina for her leadership and tenacity, Emmi for her scholarship and commitment, the board of trustees for supporting this project, and the panel of advisors for taking the time to review Emmi's paper and for sharing their perspectives with us.

As Tina Baldwin wrote in the introduction, there should be three more reports that focus on: (1) consequences to families and other in an individual's network; (2) potential legal consequences to gatekeepers who willfully or negligently cause necessary mental health services to be delayed or denied; and (3) financial consequences to state and local resources when such mental health services are not provided in a prompt and effective manner.

Christina Baldwin

There are two groups whose influence is very different and very important in the activities that have lead me to my present activities with Spectrum Institute and The Mental Health Project. There are those who have given me experience in what is not acceptable, honest, or good for the health of our person, our souls, our democracy, and our planet. To these folks, I want to say thank you for some really tough lessons that only made me stronger and wiser.

I wish to acknowledge my Mom and Dad, John, Jan, Gulhan, Melissa, Cheryl, Linda D. and Sandy. I honor the presence and influence of each of you in my life. Diana, I really enjoyed working with you on this report. It was fun and a great learning experience. Char, we have been on quite a journey together. You will always have my love, respect, admiration, and gratitude. Thank you all from the bottom of my heart.

I wish to acknowledge Tom Coleman for his gentle being, his mentorship, his friendship, his wisdom, his trust, and his extraordinary efforts to improve the systemic delivery of guardianship and mental health care services to adults with developmental disabilities. Tom, thank you for letting me watch and participate in your seed germination projects. You are one of the finest humans I have ever met, and like Char, you will always have my love, respect, admiration and gratitude.

Emmi, there is no question your report is going to have a snowball, rolling effect on needed improvement to the mental health care and wellness of individuals with intellectual and developmental disabilities. For this, I am and will be forever grateful to all you. Thank you.

Lastly, I want acknowledge Michael and my daughter. Michael, your grace, wit, patience, sacrifices, smile, generosity, technical support, and presence have been essential to my life as well as my endeavors with Spectrum Institute, The Mental Health Project, and other activities related to making the lives of people with developmental disabilities matter. To me, you are the quintessential mentor, supporter, friend, and soul mate. Thank you, sweetheart.

And, mi dulce hija, you have taught me so much about love, truth, non-violence, and the appreciation of trees. I really appreciate your help “growing me up”. Thank you.

Emmi Deckard

I would like to thank Tom Coleman for posing the topic of this report and starting the groundwork research. I would also like to thank Christina Baldwin for being a constant cheerleader throughout the process. Both have been remarkable mentors throughout the process and incredibly accommodating. To all of the clients and leadership at TRAX Equestrian Center, thank you for introducing me to disability communities and all of the power that they have.

Appendix A

Comments Submitted by Advisors to Spectrum Institute's Mental Health Project

Meriam Bendat, J.D., Ph.D., January 5, 2022.

"Overall, the report is well-researched and well-written. My most significant critique is that the report concludes that people with IDD **"are having their rights violated"** without elaborating on any applicable laws in the body. The report does cite to "principles" supported by various organizations, but principles are not rights. Given your interest in reforming the delivery of mental health care to be ADA-compliant, the report would benefit from a section addressing the ADA. I believe that any legal discussion should also address MHPAEA and ACA (which requires network adequacy for qualified health plans).

A few additional nits:

Page 4 of the report states that "Cognitive-behavioral therapy is **another** approach which is ...", but the preceding sentence concerns "psychotherapy" in general. Since no specific therapeutic modality is implicated by that prior sentence, "another" should probably be changed to "one."

Another sentence on page 4 states that "Multiple studies support the **idea** that dually diagnosed people ..." I think the use of "idea" weakens the sentence. How about stating, "... support that dually diagnosed people" instead?

Page 6 states that "Also, as previously discussed, this form of healthcare has been essentially dismissed as a feasible alternative due to excessive **regulation** from insurance companies which prevents patients from integrating their healthcare." But insurance companies don't regulate. They "micromanage" and/or "misdirect."

Jenny Farrell, Esq., January 18, 2022.

"..... I was impressed with it and I do hope it helps draw some attention to this community!"

Virginia Focht-New, PhD, PMH-CNS, BC., January 15, 2022.

"This article/white paper offers a succinct view of people with ID/IDD and co-occurring mental health conditions. The information has a flow that builds from general to more specific. The writing is articulate and uses people first language. Headings offer a view of the overall paper. The references generally address literature written in the past 10 years and represent a range of journals. The annotated bibliography offers a rationale for the choices of articles. A discussion of diagnostic overshadowing was valuable and relevant. Strong arguments are made throughout the paper for the disparities of treatment and the needs of the people.

I would like to offer some suggestions to further strengthen the article's stance and presentation.

Audience for the report:

If this report is going to be offered to a group of legislators who may or may not know much about people with ID/IDD then there needs to be a bit more background information. For instance, In the Munir article - there are statistics that people with ID/IDD are about 1-3% of the overall population and up to 40% of these individuals have a mental health condition (the article makes note of the 40%). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4814928/pdf/nihms770504.pdf

It might help to add a comparison to the general population. About 20% of the general population in the US have a mental health condition (about 51 million people). https://www.nimh.nih.gov/health/statistics/mental-illness

For context? Prevalence of schizophrenia is about 0.25 – 0.64% https://www.nimh.nih.gov/health/statistics/schizophrenia

Consider situating ID and DD (Autism Spectrum) in "Neurodevelopmental disorders" which is consistent with the DSM-5 (a document that might be known to legislators).

National Core Indicators has some statistics in a 2019 report that might be helpful. https://www.nationalcoreindicators.org/upload/core-indicators/NCI_DualDiagnosisBrief_Oct072019.pdf

Terminology:

I wonder if people not familiar with ID and DD will be confused by the use of ID (page 2 first paragraph) as the focus, but IDD is used throughout the report? It might help to say that there are a range of terms used that refer to a group of people who are neurodiverse. For this report … will be used. There is a Spectrum article where the author refers to the DSM-5 and uses *ID/IDD. And* NIH discusses the use of IDD as most current (2021). https://www.nichd.nih.gov/health/topics/idds/conditioninfo

Also "dual diagnosis" is discussed in the beginning of the report and then not used consistently in the report. People dually diagnosed with IDD and a psychiatric disorder is sometimes used. I suggest using consistent language. Here is NADD's definition. https://thenadd.org/our-mission/

The third term clarification is with "mental illness," "psychiatric disorders," "psychological disorders" and "mental health disorders." Consistency in terms may help the readers to understand that the report is focused on one area – e.g., mental health conditions (this term has less stigma attached to it than those with "disorders").

Page 2 I would avoid characterizing mental health conditions as "behavioral disorders" also avoid using "aggression" as a mental health disorder. It is counter to the discussion of diagnostic overshadowing.

Here is a SAMHSA resource https://www.samhsa.gov/find-help/disorders

The following are ideas are offered to strengthen the importance of addressing the lack of resources for people with a dual diagnosis:

I think that stating how long people have written about people with dual diagnosis (for years) could add to the significance of this issue. I see this point on page 7 and wonder if it should also be at the beginning of the report. For instance, Closing the Gap

was published in 2001. I also found an abstract for an article published in 1982 about disparities in mental health care for people with ID (then mental retardation).

A discussion of trauma is offered and focuses on the increased risk of trauma due to a mental health condition. There is evidence that untreated trauma is a contributing factor to mental health conditions. https://onlinelibrary.wiley.com/doi/epdf/10.1111/jar.12872

The Traumatic Stress Institute says that people with DD are 4 times more likely to experience trauma. https://www.traumaticstressinstitute.org/trauma-and-developmental-disabilities/

NIH also supports that people with ID/IDD are vulnerable to trauma and that the trauma may lead to mental health conditions. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6994449/

Page 4 “Cognitive-behavioral therapy is another approach which is generally considered to be a promising effective treatment for individuals with ID [5].” There are a range of therapies that people with ID/IDD can benefit from including EMDR, biofeedback, neurofeedback. The more that people see that people with ID/IDD can benefit from mental health treatment will strengthen your point here. The point about adapting therapy to the individual’s needs is valuable and applies to all people.

Page 5 “…solely by diagnosis rather than the presentation and healthcare goals of the patient… Do you mean presentation of symptoms?

Page 6 (…the vast network of caretakers that individuals with IDD may interact with - including social workers, healthcare providers, and educators…) I wonder if direct service professionals should be added to this list of caretakers since they represent the majority?

“However, current treatments for people with IDD still recommend isolation and sometimes institutionalization upon diagnosis.” Maybe segregation rather than isolation? Segregation of services is an issue even outside of congregate settings.

Page 7 Somewhere in this discussion of barriers maybe add a sentence about the reluctance of clinicians to provide treatment because they “don’t know how to work with people with ID/IDD.” The NCI report also speaks to the a disconnect between systems (MH and ID/IDD).

The overall discussion really addresses each area succinctly and makes valuable points!

I have worked with people whose life has been shortened by over medication, which may be a substitute for more adequate mental health care. I found an article (2018) that supports this. https://journals.sagepub.com/doi/full/10.1177/2042098618782785

Page 9 I think this sentence needs a citation. “People who are diagnosed with both IDD and a mental health disorder impact the economy, whether that be in the form of government assistance or institutionalization.”

Page 9 “Mental Facilities and Incarceration” Mental Health Facilities?

Page 9 “…emergency departments, hospitalizations, and readmissions [15].” How do people use more “readmissions”?

Page 10 "…suggesting that treatments are not as effective for this population." I think that this also suggests that clinicians are not effectively prepared to offer services that people need?

I wonder if it would be helpful to add the general population life expectancy of 77.8 in 2020 https://www.cdc.gov/nchs/data/vsrr/VSRR10-508.pdf

Page 11 Compare this with the life expectancy of people with ID/IDD of about 50 to 60 years old https://pubmed.ncbi.nlm.nih.gov/25994364/

Page 11 "…lead to patients being a danger…" It's ok to change terms from an article to be in sync with the article's terminology. Could "patient" be "people" instead?

Page 11 Suicide is in the heading but not mentioned in the body.

General population suicide rates: https://www.nimh.nih.gov/health/statistics/suicide

Information about people with ID/IDD and suicide: https://cdn.doctorsonly.co.il/2011/12/2006_4_5.pdf

Conclusion "The barriers outlined in this paper make it clear that people with IDD struggle to obtain mental health services and are having their rights violated in the process." I think it would be fair to add that you have made a case for the need for treatment along with the struggles to get services.

I want to again say that this report is very well written and organized. The information is presented in a sensible flow that builds on information and yet is concise. My suggestions are meant to strengthen the information here."

Dr. Matthew P. Janicki, Ph.D., January 9, 2022.

"[Emily] did a nice job on the paper you forwarded. I would caution her, however, of problems with two assumptions that underpin her paper. First, is the lack of discrimination between children with mental health conditions and adults. There are many different dynamics and social care solutions between the two and mixing data between the two can be misleading. My suggestion is to only draw from the adult health literature - unless the paper can be parsed into two segments - MH and childhood, and MH and adulthood. Second, the use of the terms intellectual disability, developmental disabilities, and intellectual and developmental disabilities tend to be used interchangeably without specific context (this is an error made by many research reports that confuse the terms or at minimum do not identify them more clearly in their subjects). Most of the literature is related to ID and ID with co-incident conditions. There is little data on other conditions under the umbrella of DD related to adult mental health. Intertwining the two can lead to misleading data and interpretations. I would recommend sticking with ID as the primary focus and then having sections of some of the DDs. That would be more accurate in presenting the data. Also, with respect to MH, parsing on serious mental illness (SMI) and behavioral problems is important as the two often have differing underlying causes and treatments (and reimbursements). The sections on care and funding are important and warrant special attention as no matter what the underlying issues of who has what, all suffer from inequities in health care and access to knowledgeable clinicians. Overall,

the analyses are well thought out, but I would counsel cleaning up the front end so that population covered is explicit.

Hope this helps."

Dr. Matthew P. Janicki, Ph.D., January 11, 2022.

"If it helps, I have enclosed an excerpt from a report that was recently done on cognitive impairment and neuroatypical conditions explaining the rationale for parsing terms:

First, a commentary on the terminology used for some of the conditions included in this report. We have chosen to use terms that are most prevalent in the literature when speaking about the conditions. However, a note on the distinction between ID and developmental disability (or disabilities). In some jurisdictions these two terms are used indistinguishably, with ID being encompassed by developmental disability. However, there is a significant difference. According to the WHO, ID "means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence) … [which] results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Similarly, the American Association on Intellectual and Developmental Disabilities notes that an ID is "characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 22." In both definitions, the core factor is impaired intellectual functioning. Sometimes, the term 'intellectual and developmental disabilities' is used to represent a collective of conditions, but it introduces confusion and lacks precision when related to defining specific older age neurodegenerative conditions. (Get citation)

Conversely, developmental disabilities are a "group of conditions due to an impairment in physical, learning, language, or behavior areas *** [which] begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime." Further, according to the CDC, developmental disabilities include ADHD, ASD, cerebral palsy, hearing loss, ID, learning disability, vision impairment, and other developmental delays. In many individuals with developmental disability, innate intellectual functioning is not impaired. However, in many cases persons with ID may also have a coincident developmental disability (e.g., ASD, cerebral palsy, etc.). As clinical diagnoses require precision and fit with coding in accord with medical classification and payment systems, we opted for clinical categories rather than political or functional definitions.

Additionally, as most of the lifelong cognitive disability-related research reported in the dementia literature refers to participants with ID, we parsed on the conditions normally included under 'developmental disabilities' and included only those relevant to discussions of older age neuropathologies. Although there is a limited amount of literature present, but growing interest, we also included ASD, and cerebral palsy in this report. Because of the wealth of research literature on ID, we also parsed ID into three groups of relevance, general ID, ID with coincident mental health issues, and DS.

That said, I agree it is quite difficult to discern the actual population being discussed in research reports and most writers are quite sloppy in their use of the terms. This is compounded by the way that people with intellectual disability are classified. For example, many have compound conditions -- such as cerebral palsy and intellectual disability, or Down syndrome and autism, etc. These characterizations of individuals in reports are too often referred to as having a developmental disability -- which is a valid designation, but is like speaking of apples and oranges under fruit. The condition characteristics are quite different and impact function, longevity, and cognitive abilities in varying ways. The problem you face is similar - what exactly are you describing in your paper? My suggestion is to point out these distinctions in the front end of the paper and then note that you will report the term used by the author when relating to some factor. I would also suggest commenting that some of the findings may be inaccurate or confounded by the lack of precision in terminology used in the reports/ articles cited.

The key notion is that often facts about people with certain conditions are based upon generalizations that are not accurate. For example, for many years the literature assumed a high rate - and predominant early onset - of dementia in persons with intellectual disability. In reality, these conclusions were drawn from adults with Down syndrome and did not apply to the 'population' of adults with intellectual disability. That led to a myth that was prevalent in the literature for many years -- and is still repeated in some reports.

If it helps, I've attached an article (Janicki, M. P., McCallion, P., Splaine, M., Santos, F. H., Keller, S. M., & Watchman, K. (2017). Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Nomenclature. Intellectual and developmental disabilities, 55(5), 338–346. https://doi.org/10.1352/1934-9556-55.5.338) on nomenclature that might be of interest."

Marshall Kapp, J.D., M.P.H, January 4, 2022

"Thanks for the opportunity to review this report.

The author does an excellent, persuasive job of documenting the problem/need in this important area of human services and public policy.

My suggestion is that the likelihood of meaningful positive responses by states would be greatly enhanced if the report contained **specific,** actionable recommendations to be included in legislation and/or Executive Actions. Model legislative language or the citation of current good models of state activity (if any such exist) would be most helpful. I know that is asking a lot, but if I were a busy state legislator with lots of items on my agenda competing for my attention, I would read the current version of this report and say, "OK, I'm convinced there is a real human need here, but I have limited time and energy for 'beginning a general dialogue on system reform.' What specifically do you want me to do in my legislative capacity tomorrow?"

Biza Stenfert Kroese, BSc, MSc, PhD., January 17, 2022.

“I have read Emmi’s draft report and think it’s very good: clearly written, well-structured and full of useful information for policy makers as well as clinicians and service users.

I attach a chapter (Stenfert Kroese, 2021 ‘Trauma-informed cognitive behavioral psychotherapy’. In: N. Beail, P. Frankish and A. Skelly (Eds.) Trauma and intellectual disabilities: Acknowledgement, identification and intervention. Pavilion Publishing) on CBT and EMDR treatment for trauma with some relevant research studies mentioned. http://www.pavpub.com/learning-disability/trauma-and-intellectual-disability-acknowledgement-identification-intervention.

The point made in the report that people with DD are more likely to suffer trauma and yet have less access to treatment is so important and perhaps some additional information on what the evidence base is for efficacy may be useful?”

Spectrum *Institute*

Mental Health Project

https://spectruminstitute.org/mental-health-project/

Public Comment

JENIFER MICK
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May 15, 2022

CPGC Board,

I have been a professional guardian for thirteen years, having been in the first graduating class of the UW program. I have watched the changes regarding how professional guardians are viewed and how the board interacts with them. When I first started the board was supportive, open to assisting guardians, and worked with them to make the profession better and better.

Things started to change in what I call, The Dark Times, when the board became punitive, disrespectful, and some of the employees actually seemed to embrace trying to professionally attack CPGs. Once this person left supposedly things were going to change and the board stated that they wanted to work with CPGs. I admit, I had my doubts.

However, after reading the minutes from this last board meeting, I know my doubts were well founded.

"Mr. Vohr asked the Board if it feels it has any role in supporting professional guardians. Judge Kiesel replied the Board follows GR 23, Regulations, etc. and has attempted to make the Board more accessible to CPGs, such as including comments submitted by CPGs. As president of WAPG he has to "dig" people out from past experiences with the Board." Mr. Vohr is completely correct, I gave up on the board years ago as a bureaucratic waste whose main purpose seemed to be to find ways to demonize CPGs in favor of a more controllable Office of Public Guardianship. I don't really know any CPGs who don't see the board as dismissive of their knowledge or experience as well as naive about what being a guardian is really like and what it takes to be successful.

"Staff noted that there were time constraints on making the training available and invited anyone who wishes to provide comments on the training to please submit their input." Time constraints don't give the board an excuse to limit CPGs or their organizations input into changes that directly affect them.

"Judge Kiesel asked Mr. Vohr if WAPG is still providing webinars and seminars rather than one-on-one training. CPGs are training CPGs. These are good intentions, but inadequate mentors." Are you kidding me? Who best to mentor than someone actually doing the job rather than sitting behind a desk?

"Judge Lewis remarked that WAPG's proposed participation on Board Committees, such as Applications or Standards of Practice would not be appropriate. However, if WAPG is interested in becoming involved with Education, DEI or Regulations Committees, it is welcome to submit public comments." Yes, we wouldn't want the people on the front lines to contribute any insight into who might have the amazing talent to be good at guardianship. Why would they be smart enough to be able to speak to SOPs? It really shows how inept and lowly the board sees CPGCs.

"Judge Kiesel observed that it is interesting that CPGCs are taking a more critical look at their profession." Why would this be interesting? Would it not be normal for any highly skilled professional to take a critical look at their profession? Do we not deal with society seeing us as horrible people who just want to take away people's rights and get their money? Do we not feel we have been punched in the gut every time we hear about another CPG being accused of violating their duty, of stealing funds, of not treating their clients well? That statement just shows that the board thinks we just live in our own little bubble, out for ourselves.

I will not be doing guardianship for much longer for many reasons. It is a very hard vocation. You are never off duty/on-call. The public in general is at the best wary of us, at the worst, thinks we are all crooks. We fight the system nearly every day to get our clients what they deserve. We deal with a society who discards those they deem not useful. The board has a tough job, I realize that. But throwing some breadcrumbs our way to placate us but withhold respect for the job we do is wrong. And it seems to be the way the board has chosen to go which is a shame.

Sincerely,

Jenifer Mick, BS, MG, GAL, CPG

GR23

Rule for Certifying Professional Guardians

Open Public Meetings

GR 23

RULE FOR CERTIFYING PROFESSIONAL GUARDIANS AND CONSERVATORS

(a) Purpose and Scope. This rule establishes the standards and criteria for the certification of professional guardians and conservators as defined by RCW 11.130.010 (26) and prescribes the conditions of and limitations upon their activities. This rule does not duplicate the statutory process by which the courts supervise guardians and conservators nor is it a mechanism to appeal a court decision regarding the appointment or statutory duties of a professional guardian or conservator.

(b) Jurisdiction. All professional guardians and conservators who practice in the state of Washington are subject to these rules and regulations. Jurisdiction shall continue whether or not the professional guardian and conservator retains certification under this rule, and regardless of the professional guardian and conservator's residence.

(c) Certified Professional Guardianship and Conservatorship Board.

(1) Establishment.

(i) Membership. The Supreme Court shall appoint a Certified Professional Guardianship and Conservatorship Board (Board) of 12 or more members. The Board shall include representatives from the following areas of expertise: professional guardians and conservators; attorneys; advocates for individuals subject to guardianship and conservatorship; courts; state agencies; and those employed in medical, social, health, financial, or other fields pertinent to guardianships and conservatorships.

(ii) Terms. The term for a member of the Board shall be three years. No member may serve more than three consecutive full three-year terms, not to exceed nine consecutive years, including any unfilled term. Terms shall be established such that one-third shall end each year. All terms of office begin October 1 and end September 30 or when a successor has been appointed, whichever occurs later.

(iii) Leadership. The Supreme Court shall designate the Chair of the Board. The Board shall designate the Vice-Chair, who shall serve in the absence of or at the request of the Chair.

(iv) Vacancies. Any vacancy occurring in the terms of office of Board members shall be filled for the unexpired term.

(2) Authority. The Court authorizes and grants to the Board jurisdiction to oversee the certification, regulation, investigation and discipline of professional guardian and conservators and related agencies.[1]

(3) Duties and Powers.

(i) Applications. The Board shall process applications for professional guardian and conservator certification under this rule. The Board may delay or deny certification if an applicant fails to provide required information.

(ii) Standards of Practice. The Board shall adopt and implement policies or regulations setting forth minimum standards of practice which professional guardians and conservators shall meet.

(iii) Training Program. The Board shall adopt and implement regulations establishing a professional guardian and conservator training program.

(iv) Examination. The Board may adopt and implement regulations governing the preparation and administration of certification examinations.

(v) Recommendation of Certification. The Board may recommend certification to the Supreme Court. The Supreme Court shall review the Board's recommendation and enter an appropriate order.

(vi) Denial of Certification. The Board may deny certification. If the Board denies certification, it shall notify an applicant in writing of the basis for denial of certification and inform the applicant of the appeal process.

(vii) Continuing Education. The Board may adopt and implement regulations for continuing education.

(viii) Grievances and Disciplinary Sanctions. The Board shall adopt and implement procedures to review any allegation that a professional guardian and conservator has violated an applicable statute, fiduciary duty, court order, standard of practice, rule, regulation, or other requirement governing the conduct of professional guardians and conservators. The Board may take disciplinary action and impose disciplinary sanctions based on findings that establish a violation of an applicable statute, duty, court order, standard of practice, rule, regulation or other requirement governing the conduct of professional guardians and conservators. Sanctions may include decertification or lesser remedies or actions designed to ensure compliance with duties, standards, and requirements for professional guardians and conservators.

[1]This section codifies a central tenet of the Supreme Court's decision re: In the Matter of Disciplinary Proceeding Against Petersen 180 Wn. 2nd 768 (2014)

(ix) Investigation. The Board may investigate to determine whether an applicant for certification meets the certification requirements established in this rule. The Board may also investigate to determine whether a professional guardian and conservator has violated any statute, fiduciary duty, court order, standard of practice, rule, regulation, or other requirement governing the conduct of professional guardians and conservators.

(x) Authority to Conduct Hearings. The Board may adopt regulations pertaining to the orderly conduct of hearings.

(a) Subpoenas. The Chair of the Board, Hearing Officer, or a party's attorney shall have the power to issue subpoenas.

(b) Orders. The Chair or Hearing Officer may make such pre-hearing or other orders as are necessary for the orderly conduct of any hearing.

(c) Enforcement. The Board may refer a Subpoena or order to the Supreme Court for enforcement.

(xi) Disclosure of Records. The Board may adopt regulations pertaining to the disclosure of records in the Board's possession.

(xii) Meetings. The Board shall hold meetings as determined to be necessary by the Chair.

(a) Meetings of the Board will be open to the public except for executive session, review panel, or disciplinary meetings prior to filing of a disciplinary complaint or

(i) proceedings concerned with granting, suspending, revoking, or denying professional guardian and conservator certification;

(ii) any disciplinary proceedings involving a CPGC; or

(iii) any portion of a meeting which relates to any other quasi-judicial matter between named parties as distinguished from a matter having general effect on the public or on a class or group.

(b) Nothing in this General Rule 23 may be construed to prevent the Board from holding an executive session during a regular or special meeting:

(i) To discuss with legal counsel representing the Board matters relating to Board enforcement actions, or to discuss with legal counsel representing the Board litigation or potential litigation to which the Board, or a member acting in an official capacity is, or is likely to become, a party, when public knowledge regarding the discussion is likely to result in an adverse legal or financial consequence to the Board. This subsection (xii)(b)(i) does not permit the Board to hold an executive

session solely because an attorney representing the Board is present. For purposes of this subsection (xii)(b)(i), "potential litigation" means matters protected by RPC 1.6 or RCW 5.60.060(2)(a) concerning:

A. litigation that has been specifically threatened to which the Board, or a member acting in an official capacity is, or is likely to become, a party;

B. litigation that the Board reasonably believes may be commenced by or against the Board or a member acting in an official capacity; or

C. litigation or legal risks of a proposed action or current practice that the Board has identified when public discussion of the litigation or legal risks is likely to result in an adverse legal or financial consequence to the Board.

(ii) To receive and evaluate complaints or charges brought against a Board member or staff. However, upon the request of such Board member or staff, a public hearing or a meeting open to the public shall be conducted upon such complaint or charge.

(c) Before convening in executive session, the meeting chair shall publicly announce the purpose for excluding the public from the meeting place, and the time when the executive session will be concluded. The executive session may be extended to a stated later time by announcement of the meeting chair.

(d) Board Committee meetings shall be open to the public when (i) the committee acts on behalf of the governing body, conducts hearings, or takes testimony or public comment and (ii) the Committee meetings, or relevant portions thereof, are not otherwise exempt from public session or eligible for executive session pursuant to these GR 23 provisions.

(e) The Board shall not adopt any resolution, rule, regulation, order, or directive, except in a meeting open to the public and then only at a meeting, the date of which is fixed by Board bylaws or regulation. Any action taken at meetings failing to comply with the provisions of this subsection shall be null and void. This subsection does not apply to any actions relating to matters set forth in GR 23 (c)(3)(xii)(a)(i)-(iii).

(xiii) Fees. The Board shall establish and collect fees in such amounts as are necessary to support the duties and responsibilities of the Board.

(4) Board Expenses. Board members shall not be compensated for their services. Consistent with the Office of Financial Management rules, Board members shall be reimbursed for actual and necessary expenses incurred in the performance of their duties. All expenses shall be paid pursuant to a budget submitted to and approved by the Supreme Court. Funds accumulated from examination fees, annual fees, and other revenues shall be used to defray Board expenses.

(5) Agency. Hearing officers are agents of the Board and are accorded rights of such agency.

(6) Immunity from Liability. The Board, its members, or agents, including duly appointed hearing officers, shall enjoy quasi-judicial immunity if the Supreme Court would have immunity in performing the same functions.

(7) Conflict of Interest. A Board member should disqualify himself or herself from making any decisions in a proceeding in which his or her impartiality might reasonably be questioned, including but not limited to, when the Board member has a personal bias or prejudice concerning a party or personal knowledge of disputed evidentiary facts concerning the proceeding.

(8) Leave of Absence. The Board may adopt regulations specifying that a Board member who is the subject of a disciplinary investigation by the Board must take a leave of absence from the Board. A Board member may not continue to serve as a member of the Board if the Board or Supreme Court has imposed a final disciplinary sanction on the Board member.

(9) Administration. The Administrative Office of the Courts (AOC) shall provide administrative support to the Board and may contract with agencies or organizations to carry out the Board's administrative functions.

(d) Certification Requirements. Applicants, Certified Professional Guardians~~s~~ and Conservators, and Certified Agencies shall comply with the provisions of Chapter 11.130 RCW. In addition, individuals and agencies must meet the following minimum requirements.

(1) Individual Certification. The following requirements apply to applicants. An individual applicant shall:

(i) Be at least 21 years of age;

(ii) Be of sound mind;

(iii) Have no convictions of a crime, or court or administrative proceeding findings, involving dishonesty, neglect, abuse, or use of physical force;

(iv) Have no convictions of a crime, or court or administrative proceeding findings, relevant to the functions the individual would assume as a guardian or conservator;

(~~i~~v) Possess a high school degree or GED equivalent and at least five full years' experience working in a discipline pertinent to the provision of guardianship and conservatorship services, or possess an associate's degree from an accredited institution and at least four full years' experience working in a discipline pertinent to the provision of guardianship and conservatorship services, or a baccalaureate degree from an accredited institution and at least two full years' experience working in a discipline pertinent to the provision of guardianship and conservatorship services, or a Masters,

J.D., Ph.D., or equivalent advanced degree from an accredited institution and at least one year's experience working in a discipline pertinent to the provision of guardianship and conservatorship services;

(v) The experience required by this rule is experience in which the applicant has developed skills that are transferable to the provision of guardianship and conservatorship services and must include decision-making or the use of independent judgment for the benefit of others, not limited to individuals subject to guardianship or conservatorship, in the area of legal, financial, social services or healthcare or other disciplines pertinent to the provision of guardianship and conservatorship services;

(vii) Have completed the mandatory certification training.

(viii) An individual certified under this General Rule prior to January 1, 2022 and in good standing under all Board regulations will automatically continue to be certified as a Certified Professional Guardian and Conservator (CPGC) as of January 1, 2022.

(2) Agency Certification. Agencies must meet the following additional requirements:

(i) All officers and directors of the corporation must meet the qualifications of RCW 11.130.090 for guardians and conservators;

(ii) Each agency shall have at least two (2) individuals in the agency certified as professional guardians and conservators, whose residence or principal place of business is in Washington state and who are so designated in minutes or a resolution from the Board of Directors; and

(iii) Each agency shall file and maintain in every guardianship and conservatorship court file a current designation of each certified professional guardian and conservator with final decision-making authority for the individual subject to guardianship or individual subject to conservatorship.

(3) Training Program and Examination. Applicants must satisfy the Board's training program and examination requirements.

(4) Insurance Coverage. In addition to the bonding requirements of chapter 11.130.040 RCW, applicants must be insured at all times in such amount as may be determined by the Board and shall notify the Board immediately of cancellation of required coverage.

(5) Financial Responsibility. Applicants must provide proof of ability to respond to damages resulting from acts or omissions in the performance of services as a guardian or conservator. Proof of financial responsibility shall be in such form and in such amount as the Board may prescribe by regulation.

(6) Application under Oath. Applicants must execute and file with the Board an approved application under oath.

(7) Application Fees. Applicants must pay fees as the Board may require by regulation.

(8) Disclosure. An applicant for certified professional guardian and conservator or certified agency shall disclose upon application:

(i) The existence of a judgment against the applicant arising from the applicant's performance of services as a fiduciary;

(ii) Any court finding that the applicant has violated its duties as a fiduciary or has violated federal or any state's consumer protection act or violation of any other statute proscribing unfair or deceptive acts or practices in the conduct of business;

(iii) Any felony convictions;

(iv) Any criminal convictions, or any court or administrative proceeding findings, involving dishonesty, neglect, abuse, violence, or use of physical force;

(v) Any criminal convictions, or any court or administrative proceeding findings, relevant to the functions assumed as guardian or conservator;

(vi) Any adjudication of the types specified in RCW 43.43.830 and RCW 43.43.842 (laws restricting access to, and professional licensing with respect to working with, vulnerable adults and children);

(vii) Pending or final licensing or disciplinary board actions or findings of violations;

(viii) The existence of a judgment against the applicant within the preceding eight years in any civil action;

(ix) Whether the applicant is or has been a debtor in a bankruptcy, insolvency, or receivership proceeding. Disclosure of a bankruptcy filing may require the applicant or guardian and conservator to provide a personal credit report from a recognized credit reporting bureau satisfactory to the Board;

(x) The existence of a judgment against the applicant or any corporation, partnership or limited liability company for which the applicant was a managing partner, controlling member or majority shareholder within the preceding eight years in any civil action.

(9) Denial of Certification. The Board may deny certification of an individual or agency based on any of the following criteria:

(i) Failure to satisfy certification requirements provided in section (d) of this rule;

(ii) The existence of a judgment against the applicant arising from the applicant's performance of services as a fiduciary;

(iii) A court finding that the applicant has violated its fiduciary duties or has violated federal or any state's consumer protection act or violation of any other statute proscribing unfair or deceptive acts or practices in the conduct of business;

(iv) Any felony convictions;

(v) Any criminal convictions, or any court or administrative proceeding findings, involving dishonesty, neglect, abuse, violence, or use of physical force;

(vi) Any criminal convictions, or any court or administrative proceeding findings, relevant to the functions assumed as guardian or conservator;

(vii) Any adjudication of the types specified in RCW 43.43.830 and RCW 43.43.842 (laws restricting access to, and professional licensing with respect to working with, vulnerable adults and children);

(viii) Pending or final licensing or disciplinary board actions or findings of violations;

(ix) A Board determination based on specific findings that the applicant lacks the requisite moral character or is otherwise unqualified to practice as a professional guardian and conservator;

(x) A Board determination based on specific findings that the applicant's financial responsibility background is unsatisfactory.

(10) Designation/Title. An individual certified under this rule may use the initials "CPGC" following the individual's name to indicate status as "Certified Professional Guardian and Conservator." An agency certified under this rule may indicate that it is a "Certified Professional Guardian and Conservator Agency" by using the initials "CPGCA" after its name. An individual or agency may not use the term "certified professional guardian and conservator" or "certified professional guardian and conservator agency" as part of a business name.

(e) Guardian and Conservator Disclosure Requirements.

(1) A Certified Professional Guardian and Conservator or Certified Agency shall disclose to the Board in writing within 30 days of occurrence:

(i) The existence of a judgment against the professional guardian and conservator arising from the professional guardian and conservator's performance of services as a fiduciary;

(ii) Any court finding that the professional guardian and conservator violated its fiduciary duties, or has violated federal or any state's consumer protection act or violation of any other statute proscribing unfair or deceptive acts or practices in the conduct of business;

(iii) Any felony convictions;

(iv) Any criminal convictions, or any court or administrative proceedings findings, involving dishonesty, neglect, abuse, violence, or use of physical force;

(v) Any criminal convictions, or any court or administrative proceedings findings relevant to the functions assumed as guardian or conservator;

(vi) Any adjudication of the types specified in RCW 43.43.830 and RCW 43.43.842 (laws restricting access to, and professional licensing with respect to working with, vulnerable adults and children);

(vii) Pending licensing or disciplinary actions related to fiduciary responsibilities or final licensing or disciplinary actions resulting in findings of violations;

(viii) Residential or business moves or changes in employment; and

(ix) Names of Certified Professional Guardians and Conservators and they employ or who leave their employ.

(2) Not later than June 30 of each year, each professional guardian and conservator and guardian and conservator agency shall complete and submit an annual disclosure statement providing information required by the Board.

(f) Regulations. The Board shall adopt regulations to implement this rule.

(g) Personal Identification Number. The Board shall establish an identification numbering system for professional guardians and conservators. The Personal Identification Number shall be included with the professional guardian's and conservator's signature on documents filed with the court.

(h) Ethics Advisory Opinions, Comments, and Best Practices.

(1) The Board may issue written ethics advisory opinions, comments and best practices to inform and advise Certified Professional Guardians and Conservators and Certified Agencies of their ethical obligations.

(2) Any Certified Professional Guardian and Conservator or Certified Agency may request in writing an ethical advisory opinion from the Board. Compliance with an opinion issued by the Board shall be considered as evidence of good faith in any

subsequent disciplinary proceeding involving a Certified Professional Guardian and Conservator or Certified Agency.

(3) The Board shall publish opinions issued pursuant to this rule in electronic or paper format. The identity of the person requesting an opinion is confidential and not public information.

(i) Existing Law Unchanged. This rule shall not expand, narrow, or otherwise affect existing law, including but not limited to, Title 11 RCW.

[Adopted effective January 25, 2000; amended effective April 30, 2002; April 1, 2003; September 1, 2004; January 13, 2009; September 1, 2010; September 1, 2021, May 3, 2022]

GR 23 Incorporation of Open Public Meetings Act

✓ **Meetings generally open – presumption**

RCW 42.30.030
Meetings declared open and public.
*** CHANGE IN 2022 *** (SEE **1329-S.SL**) ***
All meetings of the governing body of a public agency shall be open and public and all persons shall be permitted to attend any meeting of the governing body of a public agency, except as otherwise provided in this chapter.

✓ **OPMA – by its own terms doesn't apply to certain subject areas, and so public meeting requirements don't apply to the following subject areas:**

Proceedings @ professional certifications
Proceedings @ professional discipline
Quasi-judicial proceedings

RCW 42.30.140
Chapter controlling—Application.
If any provision of this chapter conflicts with the provisions of any other statute, the provisions of this chapter shall control: PROVIDED, That this chapter shall not apply to:

(1) The proceedings concerned with the formal issuance of an order granting, suspending, revoking, or denying any license, permit, or certificate to engage in any business, occupation, or profession or to any disciplinary proceedings involving a member of such business, occupation, or profession, or to receive a license for a sports activity or to operate any mechanical device or motor vehicle where a license or registration is necessary; or

(2) That portion of a meeting of a quasi-judicial body which relates to a quasi-judicial matter between named parties as distinguished from a matter having general effect on the public or on a class or group

- ✓ **Executive session topics are itemized in OPMA. Two of the itemized executive topics are potentially relevant to the Board.**

  OPMA Litigation exceptions
  Complaints vs. Board member or staff

RCW 42.30.110
Executive sessions.
*** CHANGE IN 2022 *** (SEE **5532-S2.SL**) ***
*** CHANGE IN 2022 *** (SEE **1329-S.SL**) ***
(1) Nothing contained in this chapter may be construed to prevent a governing body from holding an executive session during a regular or special meeting: …

(f) To receive and evaluate complaints or charges brought against a public officer or employee. However, upon the request of such officer or employee, a public hearing or a meeting open to the public shall be conducted upon such complaint or charge;

(i) To discuss with legal counsel representing the agency matters relating to agency enforcement actions, or to discuss with legal counsel representing the agency litigation or potential litigation to which the agency, the governing body, or a member acting in an official capacity is, or is likely to become, a party, when public knowledge regarding the discussion is likely to result in an adverse legal or financial consequence to the agency.
This subsection (1)(i) does not permit a governing body to hold an executive session solely because an attorney representing the agency is present. For purposes of this subsection (1)(i), "potential litigation" means matters protected by RPC 1.6 or RCW 5.60.060(2)(a) concerning:
(i) Litigation that has been specifically threatened to which the agency, the governing body, or a member acting in an official capacity is, or is likely to become, a party;
(ii) Litigation that the agency reasonably believes may be commenced by or against the agency, the governing body, or a member acting in an official capacity; or
(iii) Litigation or legal risks of a proposed action or current practice that the agency has identified when public discussion of the litigation or legal risks is likely to result in

- ✓ **Meeting Chair must announce purpose of executive session before convening executive session and excluding public**

RCW 42.30.110
Executive sessions.

(2) Before convening in executive session, the presiding officer of a governing body shall publicly announce the purpose for excluding the public from the meeting place, and the time when the executive session will be concluded. The executive session may be extended to a stated later time by announcement of the presiding officer.

- ✓ **Committee Meetings – per OPMA, must be public if the Committee is acting on behalf of the governing body (and not otherwise exempt/executive session issue)**

  RCW 42.30.020
  Definitions.
  *** CHANGE IN 2022 *** (SEE **1744.SL**) ***
  As used in this chapter unless the context indicates otherwise: …

  (2) "Governing body" means the multimember board, commission, committee, council, or other policy or rule-making body of a public agency, or any committee thereof when the committee acts on behalf of the governing body, conducts hearings, or takes testimony or public comment.

- ✓ **Board actions are null and void if not taken in compliance with the public meeting rules**

  RCW 42.30.060
  Ordinances, rules, resolutions, regulations, etc., adopted at public meetings—Notice—Secret voting prohibited.
  (1) No governing body of a public agency shall adopt any ordinance, resolution, rule, regulation, order, or directive, except in a meeting open to the public and then only at a meeting, the date of which is fixed by law or rule, or at a meeting of which notice has been given according to the provisions of this chapter. Any action taken at meetings failing to comply with the provisions of this subsection shall be null and void.

Grievance Report

May, 2022

Certified Professional Guardians and Conservators
Grievance Status
May 31, 2022

New Grievances Received in May, 2022:	**4**
2022 Grievances Dismissed[1] by Board on May 9, 2022:	**3**
2022 Grievances Forwarded to Superior Court on May 9, 2022:	**7**
2022 Grievances Assigned for Investigation on May 9, 2022:	**1**

Total 2022 Grievances Received:	**45**
Total 2022 Grievances Dismissed[2]:	**16**
Total 2022 Grievances Forwarded to Superior Court:	**24**
Total 2022 Grievances Assigned for Investigation	**2**

2022 Grievances Resolved by Board[3]:

Dismissal following Court Order	**2**

Active CPGCs: 257

[1] Dismissed as Incomplete or for having No Jurisdiction
[2] Dismissed as Incomplete or for having No Jurisdiction
[3] Resolution following Investigation or Court Order

Pre-2022 Grievance Status – May, 2022	2021	2020	2019	2018	2017	2016	Total
Grievances Resolved this Month:							
Grievances Remaining Requiring Investigation*:	27	4	2	1	0	0	34

Pre-2022 Grievances Pending*	2021	2020	2019	2018	2017	2016	Total
Voluntary Surrender/Litigation:							
Conflicts Review Committee:							
ARD:		1	2				3
Forward to Court:		2				1	3
Complaint/Hearing:							
Administrative Decertification:							
Total Pending:		3	2			1	6

[*Grievances in Pending status are not counted as Grievances Requiring Investigation.]

Resolution of Pre-2022 Grievances – May 2022	2021	2020	2019	2018	2017	2016	Total
Dismissal – No Jurisdiction							
Dismissal – No Actionable Conduct	1						1
Dismissal - Administrative							
Dismissal – Insufficient Grievance	1						1
Mediated – Dismissed							
Advisory Letter 507.1							
ARD - Admonishment							
ARD - Reprimand							
ARD - Suspension							
Terminated – Voluntary Surrender							
Terminated – Administrative Decertification							
Terminated – Decertification							
TOTAL PRE-2022 GRIEVANCES RESOLVED IN MAY 2022	2						2

	2021	2020	2019	2018	2017	2016	Total
Total Grievances Received by Year	**95**	**80**	**77**	**85**	**104**	**104**	**545**
Dismissal – No Jurisdiction	9	21	15	22	30	20	**117**
Dismissal – No Actionable Conduct	47	41	39	51	60	55	**293**
Dismissal - Miscellaneous		1					**1**
Dismissal – Insufficient Grievance	7	6	5	3	1	2	**24**
Mediated – Dismissed							
Advisory Letter 507.1		2	5	3	2	4	**16**
ARD - Admonishment							
ARD – Reprimand		1		1	1	4	**7**
ARD - Suspension							
Termination – CPG Death							
Termination – Administrative Decertification	4	1	3	1	1	3	**13**
Termination – Voluntary Surrender			1	2	8	15	**26**
Termination – Decertification			5	1	1		**7**
Total Pre-2022 Grievances Resolved:	**67**	**73**	**73**	**84**	**104**	**103**	**504**

Guardians/Agencies with Multiple Grievances
May 2022

ID	Year Cert.	Unresolved Grievances	Year(s) Grievances Received
A	2015	3	2021 (1), 2022 (2)
B	2012	3	2022 (3)
C	2009	3	2021 (3)
D	2015	2	2021 (2)
E	2016	7	2021 (5), 2022 (2)
F	2014	3	2019 (1), 2021 (2)
G	2011	3	2021 (3)
H	2002	2	2021 (2)
I	2001	6	2018 (1), 2019 (1), 2020 (4)
J	2011	2	2021 (1), 2022 (1)
K	2001	3	2022 (3)
L	2006	3	2021 (2), 2022 (1)
M	2011	4	2022 (4)
		44	

Of the 60 currently unresolved grievances, 44 involve 13 Certified Professional Guardians and Conservators or Agencies with 2 or more grievances.

Regulation 708

Voluntary Surrender

708 ~~Voluntary Surrender~~Retirement or Resignation and Termination of Certification

708.1 Prior to retirement or resignation from practice, ~~A~~a CPGC or Agency ~~may voluntarily surrender certification by~~ shall notify~~ing~~ the Board, in writing, ~~of the date~~ of their intended resignation or retirement and request that their CPGC certification be terminated~~the surrender is to be effective and by complying with the requirements of this regulation~~. In order for the termination of certification to be approved, the CPGC or Agency must meet all requirements defined in Section 708.1 and 708.2. Staff of the AOC ~~staff is~~ are authorized to grant ~~voluntarily surrender status~~ termination ~~to~~ of a CPGC's (or Agenc~~ies~~y's) certification that ~~qualify under~~ meet these Regulations. AOC ~~s~~Staff denials ~~to voluntarily surrender status request must be~~ of termination of the CPGC's (or Agency's) certification will be reviewed ~~and approved~~ for approval by the Certification and Application Committee.

708.2 The ~~surrender of~~ request for termination of certification shall ~~not~~ be effective ~~until~~ when the CPGC or Agency has met the following requirements:

708.2.1 Complied with all statutory and court-ordered requirements for discharge from responsibilities as a guardian or conservator in each case in which the CPGC or Agency has been appointed, ~~with the exception that a guardian and conservator who is not a member of the individual's family and who charges fees for carrying out the duties of court-appointed guardian or conservator may retain guardianship and/or conservatorship over two individuals~~ in compliance with the definition of "Professional guardian or conservator." RCW 11.130.010 (26);

708.2.2 Filed with the Board an affidavit or declaration signed under penalty of perjury stating:

708.2.2.1 Compliance with these requirements.

708.2.2.2 The address where communications may be directed to the former CPGC or Agency, and acknowledging a requirement to keep their address current with the AOC for 36 months following ~~surrender~~ the termination of certification.

708.2.2.3 That after ~~surrender~~ the termination of certification, the former CPGC or Agency shall ~~not accept any new clients or engage in work as a CPGC or Agency unless recertified following the rules and regulations applicable to new applicants~~ comply with

the definition of “Professional guardian or conservator”. RCW 11.130.010 (26)

708.2.3 The CPGC or Agency shall file the affidavit or declaration required by this regulation within sixty (60) calendar days of the date of the written notice to the Board of the intent to retire or resign and ~~surrender~~ request termination of their CPGC or Agency certification.

708.3 Failure to file the affidavit or declaration required by this regulation or failure to comply with other statutory or court-ordered requirements regarding discharge from responsibilities as a guardian or conservator shall subject the CPGC or Agency to revocation of certification.

708.4 The CPGC or Agency may revoke the notice of intent to ~~surrender~~ terminate their certification by notifying the Board in writing.

Education Committee
Request for CEU Approval

On May 31, 2022, the Education Committee, per Regulation 205.6, provisionally approved the National Guardianship Association webinar titled ***Addressing the Needs of Transgender and Gender Diverse Communities*** for One (1) Emerging Issues CEU credit and requests that the Board make final approval of that CEU credit under Regulation 205.6. The Course information is below:

Professional Enrichment Webinar

Addressing the Needs of Transgender and Gender Diverse Communities

Thursday, June 9, 2022 @ 1 p.m. Eastern

(12 p.m. Central, 11 a.m. Mountain, 10 a.m. Pacific)

This webinar will provide an introduction to terms and definitions within the transgender and gender diverse (TGD) communities. From that foundation, we will build an understanding of the unique needs of TGD people in relation to guardianship, including name and gender marker changes on legal documentation, nondiscrimination rights, and the disparities and stigma faced by the community.

Participants:

- Will be able to better understand and define terms utilized in TGD communities.
- Will be better prepared to meet the needs of TGD people in their work.
- Will gain an understanding of the disparities and stigma faced by TGD communities.

Intended Audience: Those working with TGD communities in any legal, health, or direct service professions.

The presentation will last for 60 minutes and is eligible for one hour of continuing education credit from the Center for Guardianship Certification.

Click Here and select MORE INFO to learn more about the presenter, Mason Dunn, and to register online.

Registration ends on **June 2** or when the session is full, whichever comes first. A recording of the webinar will be made available free to NGA members following the live event.

You must be logged in to the website to register. If you try to register and can't log in, your membership may have expired. To renew, **follow these instructions**.