DISABILITY ADVOCACY CONFERENCE 2019

HOSTED BY DISABILITY RIGHTS NORTH CAROLINA

Building Skills & Growing Networks

Diverse Topics for self-advocates, family members and service providers

For an alternate version of any of the materials provided, contact Disability Rights North Carolina at 919-856-2195 or conference@disabilityrightsnc.org.

This book contains general information for educational purposes and should not be construed as legal advice. It is not intended to be a comprehensive statement of the law and may not reflect recent legal developments. If you have specific questions concerning any matter contained in this document or need legal advice, we encourage you to consult with an attorney.

Disability Rights North Carolina is a federally mandated protection and advocacy system with funding from the U.S. Department of Health and Human Services, the U.S. Department of Education, and the Social Security Administration. It is an independent 501(c)(3) nonprofit organization. Its team of attorneys, advocates, paralegals, and support staff provide advocacy and legal services at no charge for people with disabilities across North Carolina.

For additional resources, check the self-advocacy section on our website
www.disabilityrightsnc.org

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Disability Advocacy Conference
May 1, 2019

This Book Contains Materials for the Following Breakout Sessions

Table of Contents

Accessible Yoga for Disability Advocates 1

Addressing the Needs of Veterans with Disabilities 13

Best Practices for Submitting Documentation* 25

Employment Essentials: Services and Accommodations 31

EPSDT: Medicaid for Children 53

Equal Access to Health Care for Individuals with Disabilities 77

Ethical Considerations When Representing Clients with Diminished Capacity 101

Guardianship Reform in North Carolina 121

How the ADA Came to Be 125

Medicaid Transformation Listening Session 137

Medicaid Waivers: Emerging Issues & Appeal Strategies - Part 1 143

Medicaid Waivers: Emerging Issues & Appeal Strategies - Part 2 177

Restrictive Interventions in Public Schools 207

The Ins & Outs of Intake – Resources for People with Disabilities 271

The R.I.C.H Approach (Respect, Individuality, Connection & Hope) 297

Trauma Informed Legal Advocacy 301

What's on the Way at the GA? 377

**Presented as part of Medicaid Waivers: Emerging Issues & Appeal Strategies - Part 2*

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Disability Advocacy Conference
May 1, 2019

Accessible Yoga for Disability Rights Advocates

Contents

- PowerPoint Presentation Handout

Accessible Yoga for Disability Rights Advocates

Virginia Knowlton Marcus, RYT-200

A Personal Story: Accessible Yoga

Accessible Yoga

What Yoga Is (& Isn't)

- Yoga means "union"
- Yoga extends far beyond activity on a yoga mat
- Yoga is a way of being in the world & within yourself
- Yoga isn't a competitive sport
- Yoga IS for everyone

The Eight Limbs of Yoga

We think of yoga as working with the body when in fact, the essence of yoga is working with the mind. **Anyone who is able to breathe and think can do yoga.**

Yoga can help us recover from trauma by:

- Quieting the mind
- Calming the central nervous system
- Steadying thoughts and emotions
- Expanding awareness
- Reconnecting with our true nature
- Allowing time and space for empowerment and self-acceptance

Any aspect of practice can be individualized and adapted to achieve these outcomes.

We can turn our yoga mat into a zone of safety and non-judgement, and take the experience off the mat into our lives, where it is always there for us.

Access to Yoga is a Civil Rights Issue

ACCESS TO YOGA IS A MATTER OF SOCIAL JUSTICE

Virginia Knowlton Marcus

People with all types of disabilities can benefit as much as anyone from the practice of yoga. Disabled yoga practitioners recognize the tremendous power that yoga has to transform and improve our existence and relationships. It enables us to heal ourselves and the planet. We learn and we teach.

Yogis realize a broader spectrum of beneficial effects when their yoga practice extends beyond the postures, or Asanas — the third limb of yoga. Advancement in yoga is predicated on the foundational first and second limbs of yoga, the Yamas & Niyamas (restraints and observances). These principles are our guide to leading an ethical life and are essential to attaining meaningful benefits from the other six limbs of yoga.

Yoga teachers are called to assist others in achieving yoga's transformative benefits. This assistance must include everyone, regardless of ability. Offering yoga to select students based on perceived mental or physical ability, while excluding others who have disabilities and may benefit most appreciably from yoga, violates such Yamas as Ahimsa (requiring proper relationship with others), Satya (requiring action consistent with truth), and Daya (requiring efforts to alleviate suffering, such as that caused by dehumanization).

"A powerful yoga practice does not require specific physical movements. It does require us to be aware of our true relationship with others."

Similarly, exclusion based on specific characteristics such as disability violates federal civil rights law. Title III of the Americans with Disabilities Act prohibits discrimination on the basis of disability, and requires reasonable accommodations and modifications to afford people with disabilities equality of opportunity to participate. Thus, under both ancient and modern precepts, access to yoga is a matter of social justice.

Discrimination against yogis with disabilities violates the spirit of yoga and the letter of the law.

Yoga studios are charged with upholding the law just as yoga teachers are charged with elevating the collective consciousness. Unjustified exclusion of yogis with disabilities violates the law and generates negativity. Yoga asks us to honor each person and treat everyone with justice, respect and equality. In this way and in these troubled times, yoga teachers can function as peace workers and foster inclusion.

It was fitting when San Francisco was recently mobilizing against hate groups that a number of yogis, rather than counter protesting, held yoga and meditation practice outside the Civic Center. They gathered to support peace and create more space within to help people come to common understanding, according to Seva Simran Singh, who led the meditation.

As a disabled civil rights advocate, I am often locked into fight mode. Yoga improves my mental, physical and spiritual health in ways I could not have imagined, and profoundly affects my ability to connect with the peaceful energy Singh describes.

I believe that our survival depends on the recognition that we are interconnected. What happens to one, happens to us all. We cannot move forward by leaving others behind.

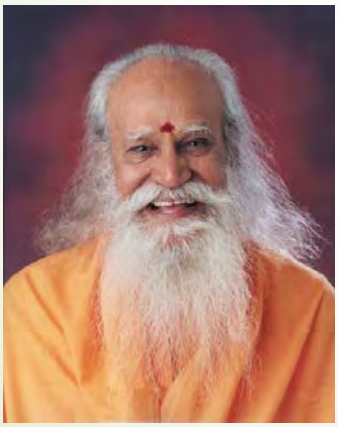
People with disabilities are our teachers. They challenge us to demonstrate our commitment to yogic principles, to honor every person, to seek beyond what we already think we know, and to willingly explore ways to ensure that all who wish to practice yoga have access.

A powerful yoga practice does not require specific physical movements. It does require us to be aware of our true relationship with others. Acrobatic yoga calls on yoga teachers and practitioners to see that our real differences are imagined, and to create welcoming spaces that bring more yogis into the fold and respect their human rights.

Virginia Knowlton Marcus is the Director of Legal Advocacy at Disability Rights California, where she previously served as the Director of Public Policy. Prior to her recent return to California, Ms. Knowlton Marcus was the Executive Director of Disability Rights Maryland. These two nonprofit legal advocacy organizations are mandated to advance the civil rights of people with all types of disabilities, of all ages, throughout their respective states for nearly 25 years. Ms. Knowlton Marcus has been advocating for people with disabilities on a broad array of critical issues at state, federal and international levels. She is the former Executive Director of the Joseph P. Kennedy, Jr. Foundation in Washington, DC where she worked on disability related federal policy, grant making, and international development projects. Her experience also includes a California Assembly Fellowship. Ms. Knowlton Marcus earned both her J.D. and B.A. in International Relations at the University of California, Davis. She has two older children and is an RYT-200 yoga instructor who taught popular yoga classes in Baltimore. She is excited to be back in California, focus of the accessible yoga movement, and sharing new ways to combine her love for yoga and passion for disability rights.

Truth is One: Paths are Many

"The light is within. It is already there. Take your time to see it." - Sri Swami Satchidananda

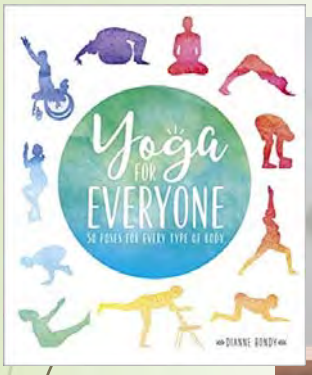


Integral Yoga Yantra

"The time has come for us to take yoga back. Yoga isn't owned by corporations or clothing companies. It is a beautiful gift to the world that we can all unwrap and enjoy. Yoga provides tools that offer us moments of peace and can lead to lives of dedication and fulfillment." - Jivana Heyman

Yoga Journal's February 2019 "Leadership Issue" and November 2018 "The Future of Yoga" Controversy

Yoga for All



Amber Karnes, Body Positive Yoga (L) & Dianne Bondy, Yoga for Everyone (R)

Melanie Klein, Yoga & Body Image Coalition®

David Emerson

- Director of the Justice Resource Institute's Center for Trauma and Embodiment in Brookline, Massachusetts.
- David led the development of Trauma Center Trauma Sensitive Yoga which was recognized by SAMHSA as an evidence-based treatment for complex trauma and PTSD.

Steffany Moonaz

- Yoga therapist, researcher, faculty at the Maryland University of Integrative Health and founder of Yoga for Arthritis; spent 8 years at Johns Hopkins University, creating and evaluating her yoga program for people with arthritis.
- Steffany now works to make yoga available to people with arthritis, educates yoga teachers and serves as a mentor for emerging researchers studying the effects of yoga for various health conditions.

Kevin Pearce

- Love Your Brain was founded by former professional snowboarder Kevin Pearce, who sustained a serious traumatic brain injury during an Olympic training run. He credits yoga and meditation for his recovery.
- Love Your Brain makes yoga practice available to people who have sustained a TBI and has grown to 29 states.

Dan Nevins

- Dan Nevins is a yoga instructor. He is also an Army veteran and double amputee as the result of an IED blast in Iraq.
- After discovering yoga's profound benefits, Dan began working to bring these practices to other veterans.
- Recognizing that many people experience trauma, he now teaches yoga all over the country. Dan believes yoga can save lives.

Restorative Yoga

- Is a slow sequence with long hold times and extensive use of props that allow the mind and body to relax deeply. It encourages gentle opening, calming, self-awareness and mindfulness. It can allow for feelings of safety, acceptance and reconnection.

Yoga Nidra

- Or "yogic sleep" is a form of guided meditation practiced while resting in savasana. Yoga Nidra balances the sympathetic and parasympathetic nervous systems, relaxes and frees the brain from stress and anxiety, and facilitates healing.

Hala Khouri

Off the Mat, Into the World

Rose Kress

Life Force Yoga

De Jur

Uprising Yoga

Durga Leela

Yoga of Recovery

Baltimore Yogis

Changa Bell, Black Male Yoga Initiative

Ali & Atman Smith and Andres Gonzalez, Holistic Life Foundation

McNairy family & friends

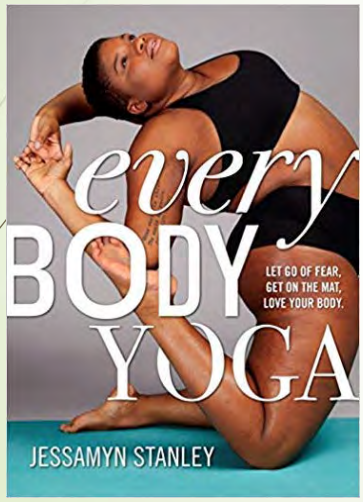
Linda Natera

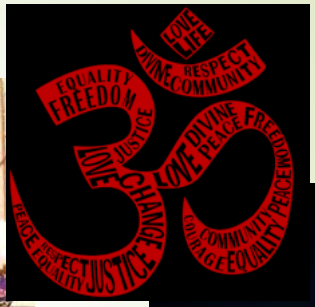
Carey Sims

Howie Shareff

Stacie Dooreck

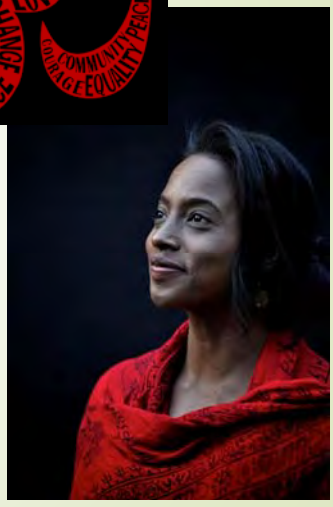
NC Yogis





Michelle C. Johnson

Kelley Carboni-Woods



Yoga and meditation can help us understand the connectedness of all things. We must learn to live in harmony or we will destroy our world.

This is a call to action along a path of peace.

Yoga practice is a way for us to breathe – live – as One.

Art by Meredith Huml

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May 1, 2019

Addressing the Needs of Veterans with Disabilities

Contents

- PowerPoint Presentation Handout

How AmericaServes Works:
A Case Study of Hurricane Florence

As a senior leader of Community Services at Camp Lejeune recently noted, "We, on base, used to pride ourselves in being self-sufficient—Hurricane Florence changed that and created a new reliance on community collaboration."
NC Serves Coastal is a proud part of that collaboration.

-Jacksonville Daily News, Editorial, Jan 7, 2019

DISASTER & RECOVERY

DISASTER & RECOVERY

96 clients across North Carolina made 207 service requests, the vast majority of which were specifically reported as disaster related.

16 Clients

had previously sought services within NCServes prior to the hurricanes

173 Requests

were served by NCServes-Coastal with the help of its sister networks

Spotlight on NCServes-Coastal's Hurricane Response:

- ✓ 62% of requests came from providers as opposed to individual clients
- ✓ The top 7 service categories made up 75% of the requests for services. These categories represent fairly high urgency needs (see table)

94% of the requests that came in during this time period have been closed. Of the closed requests, 91% have been resolved favorably.

Service Category	# Requests
Housing & Shelter	36
Income Support	21
Clothing & Household Goods	20
Food Assistance	19
Utilities	14
Mental/Behavioral Health	9
Individual & Family Support	7
Education	6
Employment	6
Benefits Navigation	6
Money Management	5
Wellness	5
Legal	5
Physical Health	4
Spiritual Enrichment	3
Social Enrichment	1
Sports & Recreation	1
Transportation	1

NCServes and Hurricane Florence

A STATE INTERCONNECTED BY PEOPLE AND TECHNOLOGY

Blake Bourne
Executive Director
Veterans Bridge Home

Paul Berry
Network Director, NCServes-Central Carolina
USO of North Carolina

Brandon Wilson
Network Director, NCServes-Western
Asheville Buncombe Community Christian Ministry

Jerrick Vernon
Network Director, NCServes-Coastal
Eastern Carolina Human Services Agency

Sheri Badger
Disability Integration Specialist
NC Department of Public Safety, Division of Emergency Management

David Laws
Service to the Armed Forces Officer
American Red Cross

Lindsay Gress
Career Center Manager
NCWorks – Division of Workforce Solutions

Hurricane Client Story

State Response

Hurricane Florence
By the Numbers[17]

- **42** storm-related fatalities
- **5,214** people and **1,067** animals rescued and evacuated
- **1,100 personnel** deployed from **35 states**
- **371 households (1,049 people)** checked into hotels through FEMA's Transitional Sheltering Assistance program
- **100,145 homes** inspected by FEMA
- **137,000 people** registered for disaster assistance
- **$125 million** in food assistance through Disaster Supplemental Nutrition Assistance Program ("DSNAP")[18]
- **The last 2 shelters** closed on November 9, 2018

"Community-based supports are vital to ensuring victims of disasters such as Hurricane Florence can recover from losses incurred. Survivors in shelters with significant community involvement and highly positive Red Cross managers and staff were better equipped to endure the stressors they were facing than those in shelters that did not provide this level of support."

Notable Recommendations:

- Counties should include their non-governmental community partners in preparing annual disaster plans.
- Local DSS should staff all shelters from the outset until they are no longer needed to support direct service providers, offer information and resources, and coordinate effective and efficient response efforts.

Excerpts from report by Disability Rights North Carolina:
The Storm *after* the Storm – Disaster, Displacement and Disability Following Hurricane Florence

AmericaServes IVMF

Key Performance Indicator: Provider Activities

Network Spotlight on NCServes-Coastal

Share of Providers Making or Receiving Referrals

Aim (2019)
80%

Where We Are (2018)
55-95%
(wide variance)

Presented at the NCServes-Coastal 2-Year IPR on January 10, 2019

Current State:

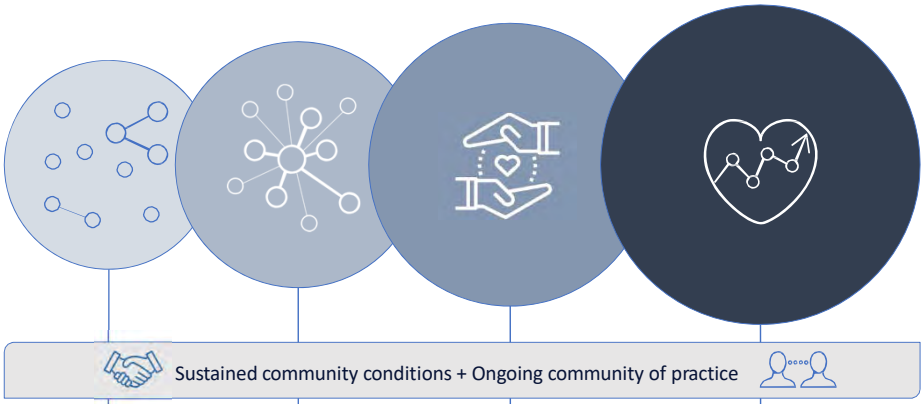
Great Team, Great Networks, Great Impact

2018:

- ❑ 14 networks operating for the full year
- ❑ Nearly doubled in scale of requests and clients
- ❑ Maintaining or improving performance at scale
- ❑ New teammates!

	2015	2016	2017	2018
Networks	3	7	13	**17+**
Providers	150	300	670	**875**
Clients	1,837	5,990	12,808	**22,123**
Service Requests	2,847	10,904	24,493	**45,875**
Time to Match (Average Days)	8.97	8.21	5.75	**5.53**
% Resolved Requests	43%*	70%	72%	**72%**

Underpinning our Current State:
The AmericaServes Theory of Change



Sustained community conditions + Ongoing community of practice

Community without network

Network creation

Improved holistic care

Transform health and human services

AmericaServes

IVMF Syracuse University

Underpinning our Current State:
The AmericaServes Theory of Change

Levels/Categories of Measures & Outcomes

Baseline
Baseline measures of service delivery and wellness.

System
Timely and appropriate referrals to providers, at scale.

Individual
Improved well-being for clients across service categories.

Population
More efficient and effective service delivery in communities.

Support
Local leadership, provider buy-in, financial support

Sustained community conditions + Ongoing community of practice

Learning
Successful dissemination of knowledge

Community without network

Network creation

Improved holistic care

Transform health and human services

AmericaServes

IVMF Syracuse University

AmericaServes

Priorities:

Driving Performance and Practice through Insights

Performance: The work of producing positive outcomes

IVMF Syracuse University

Aims that are aspirational, yet achievable.

We know they are achievable because each one has already been achieved by at least one network (in most cases several or even many networks).

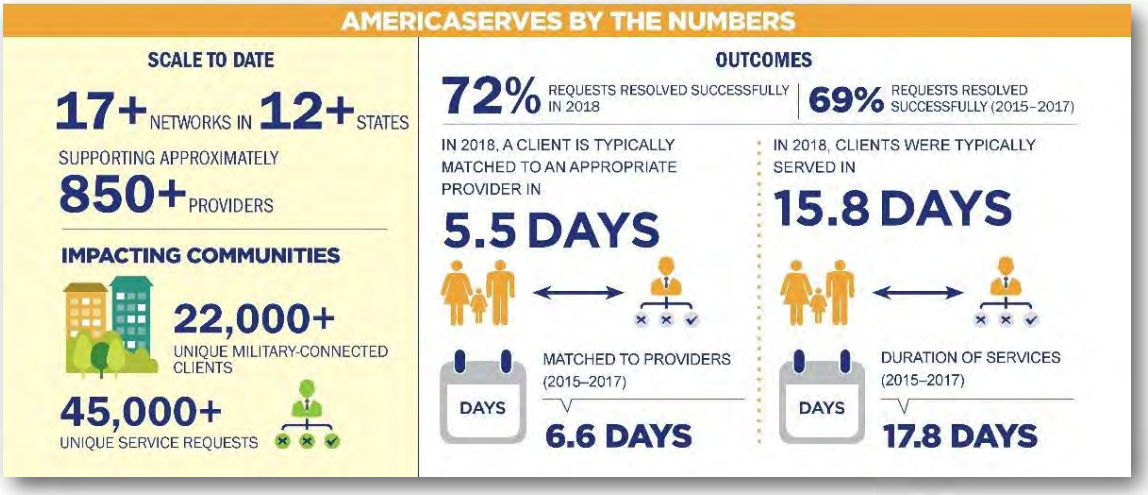
Performance Goal 1	Measure	2019 Aim
COORDINATION CENTER ACTIVITIES	**Accuracy:** % of referrals served by the first provider	96%
	Time to match: Average days to match a client to the appropriate provider	5.0 days
	Providers Receiving: % of providers receiving referrals	75%

Performance Goal 2	Measure	2019 Aim
PROVIDER ACTIVITIES	**Provider Referrals:** % of requests that come from providers	50%
	Providers Making: % of providers making referrals	50%
	Active Providers: % of providers making OR receiving referrals	80%

Performance Goal 3	Measure	2019 Aim
GROWTH	**New clients:** % growth of unique new clients	5-10%
	New requests: % growth of new service requests	5-10%
	Market share: % of veteran population in the service area that are network clients	+1 % pt

Performance Goal 4	Measure	2019 Aim
RECEPTIVE CONDITIONS	**Support:** Local community champions and leadership (e.g. advisory committees, inclusion in community meetings)	Y/N
	Sustainable funding: % of funding after 2 years delivered directly to market	50%
	Provider buy-in: Non-active providers engaging in other network activities	Y/N

17+ Communities. 12+ States. 1 Solution.



AmericaServes IVMF Syracuse University

Practice and Performance Model

We affect our *downstream* goals by acting on *upstream* indicators.
The *how* is determined at the community level.

AmericaServes

IVMF Syracuse University

AmericaServes

Priorities:

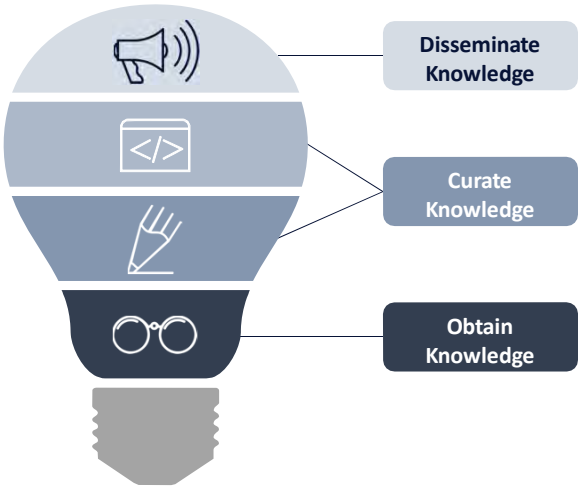
Driving Performance and Practice through Insights

Practice: The set of activities informing optimal performance

IVMF Syracuse University

Our practice activities underpin performance by collecting, organizing, and sharing what we learn from research, past practice, performance data, and our partners.

The value of our practice lies in its ability to translate inputs into meaningful insights that inform strategy for AmericaServes, health and human services, and academia.



Powered by Incredible Community Partners

Northwell Health

Pittsburgh Mercy — A Heritage of Hope

ServingTogether. Connecting Veterans. A program of EveryMind. Affiliated with AmericaServes

Veterans Bridge Home

Community Action Partnership — Helping People. Changing Lives.

USO North Carolina

Forces United

ABCCM

WestCare

AACOG — Alamo Area Council Of Governments

United Way of Tarrant County

SDUNITED

Community Service Council — Oklahoma Veteran Connections

United Way South Hampton Roads

Supported by Generous Philanthropic Partners

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Best Practices for Submitting Documenation

Table of Contents

- PowerPoint Presentation Handout

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Best Practices for Submitting Documentation:
Why Your Document Photos are Bad, and How To Improve Them

Disability Advocacy Conference – May 1, 2019

Josh Prater

Problem: I need to send this document quickly!

- Ideally, you would use a scanner device and send it by secure email. However, scanners can be expensive or hard to access, and email is often maintained in cloud servers subject to security breaches, and provided by companies (like Google) that may data mine your documents
- Email may still be okay, if it's through a reputable company
- One possible solution to lack of access to a dedicated scanning device is to use a scanner app for smart phones. Here is (hopefully) a list of good scanning apps that will make that easier:

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We don't have time for that! We have to do it FAST

- A common way of addressing this problem, especially when time is of the essence, is to use the cell phone's camera to take a photo of the document, and send that.
- This can be a quick, effective way to get an electronic copy of a document
- Bear in mind that the photo you take affects the document produced from it

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I am a master photographer and a technological genius

- Fantastic! Your documents will be beautiful. This will help in several ways:
- Your attorneys and their staff will be able to more easily read the document, saving time and resources
- Judges and court staff will more easily be able to review your documentation
- When judges are better able to read your documents, the chances that all the nuance of your case will be understood is improved

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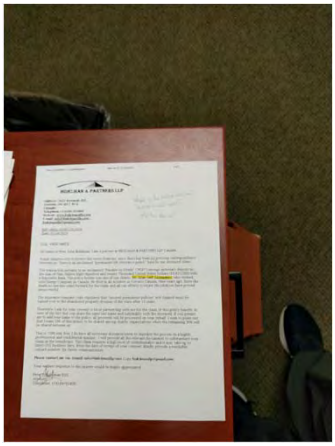
Framing

- As best you can, frame your photo so that it includes the entire document
- If you can, try to get only the document you wish to show in the frame. A showcase of your table top will not be helpful to your case
- Optical vs. Digital zoom – most phones use digital zoom, which makes photos LARGER, but not clearer. Best practice is to physically adjust the distance from lens to document, if possible



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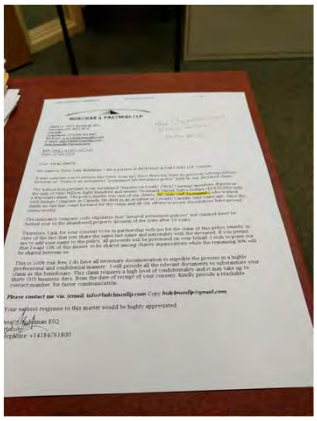
Angle

- Jaunty angles are for social media
- When photographing/scanning documents, try to hold the lens directly above/across from the center of the document
- Avoid Star Wars scans



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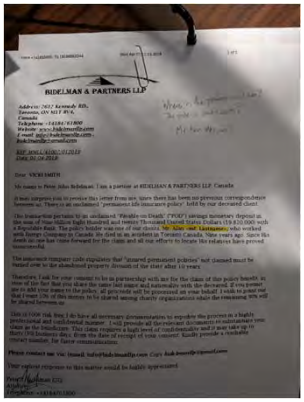
Lighting

- An important part of a good photograph or document scan is appropriate lighting
- Large shadows can obscure text or images
- Glare can also completely obscure your document



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Now what?

- You carefully framed your picture, including the entire document, and as little extraneous background as possible
- You made sure your photo was taken perpendicular to the paper, to avoid The Trapezoid
- You were careful to include enough light to avoid shadows, but not so much that your photo includes glare
- Excellent!
- Did you check the final photo before sending/uploading? A final check only takes a moment, and can make a world of difference.

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May 1, 2019

Employment Essentials:
Services & Accommodations

Contents

- PowerPoint Presentation Handout

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EMPLOYMENT ESSENTIALS: SERVICES & ACCOMODATIONS

What Will I Learn Today?

- How to obtain employment services for people with disabilities in North Carolina
- How to request a workplace accommodation
- Different types of accommodations

2

Part I: Publically-Funded Employment Services

- Several State and federal agencies provide employment services
- Lack of coordination and familiarity across agencies
- DRNC 2019 Work Report

3

The Vocational Rehabilitation Program

- Provides goods and services to people with disabilities to help them obtain, maintain, regain, and advance in employment.
- Agencies
  - Division of Vocational Rehabilitation (DVRS)
  - Division of Services for the Blind (DSB)
  - Eastern Band of Cherokee Indians
  - Department of Veterans Affairs

4

Student Employment Services

- Students with disabilities receiving special education services under an Individual Education Plan (IEP) are entitled to transition services from the school beginning at the age of 14 until graduation from high school.

5

Students Employment Services (cont.)

- Students with disabilities are entitled to pre-employment transition services (administered by VR) between and including the ages of 14-21, whether in high school or higher education.
- Services include paid work experiences, internships, self-advocacy training, and other activities to prepare young adults to transition to life after high school.

6

Local Management Entities/Managed Care Organizations (MCOs)

- MCO's manage both state-funded and Medicaid-funded behavioral health services.
- Employment services include:
  - Adult Developmental Vocational Program (ADVP),
  - Supported Employment (SE),
  - Long-Term Vocational Supports (LTVS), and
  - Individual Placement and Support (IPS).

7

Workforce Development Centers

- Part of the Department of Commerce, NC Works helps all job seekers (not only individuals with disabilities) learn about available jobs, look for work, training and education programs, and provides free access to the internet and NCWorks job database.
- More targeted services are available to individuals with disabilities ages of 14-24.

8

Employment Networks (Ens)

- May be non-profits, for-profits, or state agencies.
- Provide employment services to people who receive Social Security Disability Insurance (SSDI) under a contract with the Social Security Administration.
- Search engine is available at https://choosework.ssa.gov/findhelp/

9

Work Incentives Planning and Assistance (WIPA)

- The goal of the WIPA program is to enable beneficiaries to receive accurate information about the advantages and effects of work on their Social Security benefits.
- In North Carolina, ServiceSource assists beneficiaries in the eastern part of the State and VR assists in the western part of the State.

10

How Do I Choose?

- Basic Assistance (e.g. job / internship / apprenticeship searches, application assistance)
  - Workforce Development Centers
  - Employment Networks
- Moderate to Significant Assistance (e.g. training and education, workplace adjustment services, supported employment)
  - VR Programs
  - LME/MCOs

11

How Do I Choose? (cont.)

- Transitional Services
  - High School
  - VR Program
  - Workforce Development Centers
- Social Security Benefits Planning
  - WIPA

12

Part II: Workplace Accommodations

Three sources of accommodations:

-VR Program

-Employers

-Personal Items

13

VR Accommodations

- Rehab Engineer Evaluations,
- Job Equipment,
- Telecommunication Devices,
- Rehab Engineer Evaluations,
- Work Site Modifications,
- On the Job Training,
- Retraining

14

Employer Accommodations

The Americans with Disabilities Act of 1990 (ADA)

- 42 U.S.C. § 12101, *et. seq*.
- Federal civil rights law for people with disabilities signed into law by H.W. Bush
- Designed to eliminate discrimination and remove barriers that prevent individuals from enjoying the same opportunities that are available to persons without disabilities

15

Structure of the ADA

- **Title I:** **Employment**
- **Title II:** State and Local Government Services and Programs
- **Title III**: Private Entities Operating Public Accommodations or Commercial Facilities
- **Title IV**: Telecommunications
- **Title V:** Miscellaneous

16

Negative Rights

May not:

- Limit, segregate or classify based on disability,
- Use qualification standards that have the effect of screening out people with disabilities,
- Use standards, criteria, or other administrative methods that discriminate based on disability or perpetuate discrimination,
- Exclude or deny equal jobs or benefits to an applicant or employee because of their association with a person with a disability,
- Deprive a person of an employment opportunity because you may have to provide a reasonable accommodation,
- Deprive an applicant or employee of an employment opportunity because they may need a reasonable accommodation.

17

Affirmative ADA Rights

Must:

- Provide reasonable accommodations that do not cause an undue hardship,
- Administer employment tests in the most effective manner for including applicants and employees w/ disabilities,
- Provide appropriate auxiliary aids and services to ensure effective communication.

18

Accommodations

When may you need an accommodation:

- Job Application
- During an Employment Test
- To Maintain Your Job
- To Transfer or Advance

19

Accommodation Discrimination

2 Types:

1) **Failure to Provide Reasonable Accommodation**

2) Deprive employee or applicant of an employment opportunity because they may need a reasonable accommodation

20

Right to Accommodation

- Not automatic
- Must satisfy several conditions to establish a right to an accommodation

21

First Condition

You must have a disability

- Physical or mental impairment that **substantially limits** one or more **major life activities** OR a record of such an impairment
- Impairment is not the result of current illegal drug use, "sexual behavior disorders" such as transsexualism, compulsive gambling, kleptomania, or pyromania.

22

Second Condition

Employer must have notice of your disability

- Notice may be:
  - Self evident
  - Disclosed by you
  - Disclosed by third party
  - Obtained by employer through medical inquiry

29 CFR Pt. 1630, App. § 1630.9

23

Third Condition

You must either be qualified for the job or qualified for a vacant job that can be reassigned to you

- You are qualified for a job if you can complete the "essential" job functions **with or without reasonable accommodation/s.**
- Accommodations can eliminate or reallocate "minor" job tasks
- Job task may be essential if the position exists to perform the task, there's a limited number of employees to complete the task, or the task is highly specialized.
- 29 CFR Pt. 1630, App. § 16.30.2(n)

24

Fourth Condition

You must request an accommodation

- Don't have to say any magic words but must convey 1) what accommodation you want and 2) it's for your disability

29 CFR Pt. 1630, App. § 1630.9

- https://askjan.org

25

Fifth Condition

Accommodation must be reasonable

- Job-related
- Disability-related
- Ordinarily reasonable on its face
- Rebuttable presumption if accommodation is not reasonable on its face

29 CFR Pt. 1630, App. § 1630.9

26

Fifth Condition (cont.)

- If the reason for the accommodation is not obvious the employer can require medical verification from your doctor.
- Medical verification need only explain why the accommodation is disability-related and job-related.

29 CFR Pt. 1630, App. § 1630.9

27

Sixth Condition

Accommodation must not be an undue hardship on the employer

- Fundamentally alters the business
- Significant administrative difficulty
- Significant expense
  - Total Cost
  - Employer's financial resources
  - Resources available to offset costs

29 CFR Pt. 1630, App. §§ 1630.2(p) & 1630.15(d)

28

Sixth Condition (cont.)

If costs are an undue burden, costs may be offset by:

- VR Program
- You can pay a portion
- Tax Credits and Deductions
  - Work Opportunity Tax Credit
  - Disabled Access Tax Credit
  - Barrier Removal Tax Deduction

29

Seventh Condition

No right to requested accommodation if the employer has offered an alternative, reasonable accommodation.

- Employer may suggest alternatives
- Alternative doesn't have to be "best" option
- Employer has discretion to choose their alternative if it meets your work needs

29 CFR Pt. 1630, App. § 1630.9

30

Eight Condition

Both the employer and employee are responsible for making good faith efforts to interact with each other.

- Referred to as an interactive process
- Understand your disability-related limits
- Communicate with the employer about essential job functions, cost of the accommodation, why the accommodation meets your disability-related limits

29 CFR Pt. 1630, App. § 1630.9

31

Eight Condition (cont.)

To comply with the interactive process,

- Follow up with your request
- Be open to discussing alternatives and truthfully evaluate the effectiveness of alternatives
- Offer ways to offset the costs if its an issue
- Be reasonable! Meet your responsibilities. Don't be the one who acts in bad faith.

32

Types of Accommodations

- Employment testing (accessible testing sites, modified testing conditions, and accessible testing formats)
- Accessible job materials or policies
- Provide or alter equipment, aids, or services
- Facility alterations (making workplace readily accessible and usable)

33

Types of Accommodations (cont.)

Job restructuring (minor changes to job tasks or changing when/how tasks are completed)

- Modified work schedule (flexible hours, part-time schedule)
- Remote Work

34

Types of Accommodations (cont.)

Reassignment to vacant position (i.e. no longer qualified for current job, qualified for different job)

- Not available to applicants
- Demotion, Lateral Move, Promotion

29 CFR App. to Part 1630, § 1630.2(o)

35

Accommodation Discrimination

2 Types:

1) Failure to Provide Reasonable Accommodation

2) **Deprive employee or applicant of an employment opportunity because they may need a reasonable accommodation**

36

Screening Out

Employers cannot screen out qualified candidates with a disability because they require a reasonable accommodation

- Example. Employer selects candidate w/out a disability over candidate w/ a disability b/c candidate w/out a disability can drive to the store from time to time. Driving is a minor job task and can be reassigned.
- Has employer violated the law?

29 CFR App. to Part 1630, § 1630.15(b) and (c)

37

Contact Information

Community Access Team
Disability Rights North Carolina
Raleigh, NC 27608

919.856.2195
877.235.4210
888.268.5535 TTY
919.856.2244 fax

www.disabilityrightsnc.org

38

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT): Medicaid for Children

Contents

- PowerPoint Presentation Handout (DHHS)
- PowerPoint Presentation Handout (NHeLP)

Early and Periodic Screening, Diagnostic and Treatment Services

States Will Continue to Steward the EPSDT Benefit Guarantees

In future waiver environments, states must assure that:

- MCO's do not use a definition of medical necessity for children more restrictive than the state (EPSDT) definition;
- MCO's are trained and informed about EPSDT requirements;
- MCO's inform all families of services and access under the EPSDT benefit.
- MCO make all services listed in the Social Security Act 1905(a) available to child beneficiaries.
- *State monitoring and quality assurance strategies for MCO's are in place.*

1

Early and Periodic Screening, Diagnostic and Treatment Services

States' Will Continue to Steward the EPSDT Benefit Guarantees

In January 2017, CMS released EPSDT benefit policy guidance, in support of the integrity of the benefit in managed care business environments.

Medicaid's Final Managed Care Regulations Language:

"Each contract … must do the following: … Require that the services identified in paragraph (a)(1) of this section be furnished in an amount, duration and scope that is no less than the amount, duration, and scope for the same services furnished to beneficiaries under FFS Medicaid, as set forth in § 440.230 of this chapter, and for enrollees under the age of 21, as set forth in 42 U.S.C. § § 1396a(a)(43) and 1396d(r).

https://www.medicaid.gov/federal-policy-guidance/downloads/cib010517.pdf

2

Early and Periodic Screening, Diagnostic and Treatment Services

States' Will Continue to Steward the EPSDT Benefit Guarantees

Abstract of CMS January 2017 guidance on EPSDT benefit, in support of the integrity of the benefit in managed care business environments.

- ***States remain responsible*** for implementing the *entirety* of the EPSDT benefit, in both fee-for-services and in future waiver/managed care environments.
- Should managed care contracts be crafted which 'carve out' specific, covered services for kids (for example, preventive visits or hospital care for specific conditions) the state Medicaid Agency will remain responsible for assuring that services coverable under Sec 1905(a) which do not appear in state plan, or are coverable with policy limitations in quantity or frequency, will be made available to child beneficiaries when EPSDT's standards of medical necessity are met.
- States will continue to be responsible for annual reporting of child beneficiary participation in Early and Preventive Screening (CMS 416).

https://www.medicaid.gov/federal-policy-guidance/downloads/cib010517.pdf

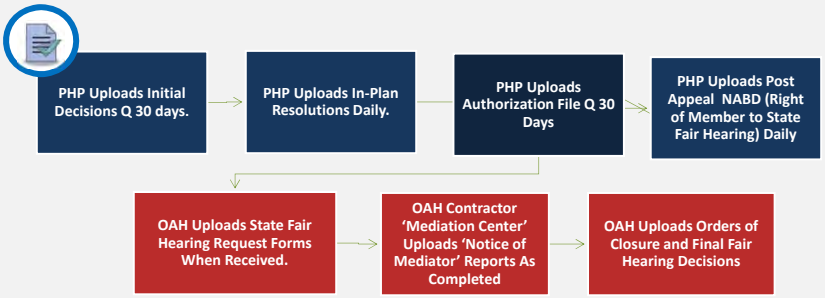
3

Monitoring Due Process Compliance

- The Appeals Clearinghouse team has developed a robust set of analytic tools and reports to monitor compliance with:
  - Federal/State Due Process stipulations
- We now track and report on:
  - **Appeal timelines compliance and closures**, by service type and MID
  - **Length of Maintenance of Service**, by MID, service type and vendor
  - **Cost of appeals**, by age groups, by service types and across time
- The Clearinghouse also has capacity to conduct quality review of letters by selection and review of samples by vendor or service type.

Medicaid Clearinghouse: A Closer Look

Medicaid Clearinghouse Monitors Lifespan of Each Adverse Determination:



Participating Partners and Functions:

- Public Consulting Group (PCG) hosts and manages technical operation of E platform.
- PCG informs all PA vendors of upload activity, Appeal Request activity and case closures in nightly secure email.
- PHP, NABD decision makers, state monitors/QA reviewers, AGO and OAH are able to access all documents by MID, date of upload, service type.

5

Adverse Benefit and Related Appeal Notices

Features of Member-Centered State Produced Notices of Adverse Benefit Determination:

- Due Process compliant
- Key Information Up Front
- Clear Visual Grids Separate Important Information
- Information is Grouped Together in Headings with Logical Flow
- Sentences are Short, Simple and Active Voice
- Common Words and Examples are used Throughout Notice
- Important Policies and Regulations Appear In Decisions

DECISION ON YOUR REQUEST FOR SERVICES

Notice Date: [INSERT DATE]	**Trackable Mail #:** [INSERT NUMBER]	**PA #:** [INSERT PA NUMBER]
This Action will take effect on: [INSERT EFFECTIVE DATE]	**Call** [VENDOR HELP LINE] **for help**	
[MEMBER OR LEGAL GUARDIAN] [ADDRESS LINE 1] [ADDRESS LINE 2] [CITY, STATE, ZIP]	[REQUESTOR NAME] [ADDRESS LINE 1] [ADDRESS LINE 2] [CITY, STATE, ZIP]	
MID: [MEMBER MID]	**DOB:** [MEMBER DOB]	**Member:** [MEMBER NAME]

[PHP NAME] manages your Medicaid health services. On [DATE OF REQUEST], you or your provider asked us to approve your request for a health service or item.

Choose an item.

IF YOU DON'T AGREE WITH OUR DECISION, YOU CAN APPEAL IT.

This letter tells you about our decision. Please read it carefully.

To ask for an Appeal, fill out and send us your Appeal Request Form. You will find it in this notice.

You can also call us to ask for an Appeal. The phone number is: [INSERT PHONE NUMBER].

The last day to ask for an Appeal is [INSERT 60TH DAY AFTER DATE OF NOTICE MAILED. IF THE 60TH DAY IS A SAT/SUN OR HOLIDAY, INSERT THE DATE FOR THE NEXT BUSINESS DAY]. You have 60 days from the date on this Notice to ask for an Appeal.

Source: "*Guide to Improving Notices of Adverse Action:*". U.S. Dept of Agriculture, Food and Nutrition Services. Sept, 2014

6

Adverse Benefit and Related Appeal Notices

Features of Decision Sections in NC Notices:

- Clear Statement of Requested Services
- Important Dates Auto-generate
- Accommodations for All Possible Circumstances Appear
- Free Text Comment Section Available When Needed.
- Format Encourages Simple and Direct Statements
- Document is Automation Friendly
- Important Policies and Regulations Appear
- Only Pertinent Sections Appear in Final Notice

YOU ASKED FOR:

Service Description	Code 1	Code 2	Plan	Request Dates	Requested Amount

WE APPROVED:

Service Description	Code 1	Code 2	Plan	Approved Dates	Approved Amount

WE DENIED:

Service Description	Code 1	Code 2	Plan	Denied Amount	Denied Dates

COMMENTS: [SEPERATELY ADDRESS EACH SERVICE CODE VOIDED/REDUCED]

[SERVICE CODE] [SERVICE DESCRIPTION]: This is different than what you requested. OR
[SERVICE CODE] [SERVICE DESCRIPTION] was voided because [text explaining reason for void].

[** NOTE: *When a complete denial of the request results from requested additional information not being received timely, use DD1.]*

DD 1: **We asked your provider to send us more information about your request to help us approve it. Your provider didn't send us the information we requested.**

- On [DATE OF REQUEST FOR ADDITIONAL INFORMATION], we asked your provider for the following important facts or documents: [BRIEF FREE TEXT STATEMENT ON ADDITIONAL INFORMATION REQUESTED].
- Without this additional information, your request did not meet criteria for approval found in [GENERAL POLICY NAME HERE]

DD 2: **We denied the following services in your request.** [DD2 IS INTENDED TO PROVIDE RATIONALE FOR EACH DENIED SERVICE WITHIN A REQUEST. REPEAT DD2, EITHER CHOICE 1 OR CHOICE 2, FOR EACH SERVICE DENIED BY VENDOR. FOR EACH SERVICE DENIED, DEPRECATE THE UNUSED ROW.]

CHOICE 1: [FOR POLICY DENIAL: DEPRECATE THIS ROW WHEN UNUSED]

[CODE] [SERVICE DECRIPTION]:

We denied the treatment, product or service your provider requested to treat your medical condition. Medicaid Health Plan policy rules found at [STATE SECTION AND GENERAL POLICY NAME HERE] guided our decision.

7

Adverse Benefit and Related Appeal Notices

Features of Decision Sections in NC Notices:

- Clear Statement of Requested Services
- Important Dates Auto-generate
- Accommodations for All Possible Circumstances Appear
- Free Text for Rationales is Isolated in Block, Making QA Straightforward
- A 'Static Text' Section is Built In When No In Plan Policy Covers Requested Service

DD 1: **We asked your provider to send us more information about your request to help us approve it. Your provider didn't send us the information we requested.**

- On [DATE OF REQUEST FOR ADDITIONAL INFORMATION], we asked your provider for the following important facts or documents: [BRIEF FREE TEXT STATEMENT ON ADDITIONAL INFORMATION REQUESTED].
- Without this additional information, your request did not meet criteria for approval found in [GENERAL POLICY NAME HERE]

DD 2: **We denied the following services in your request.** [DD2 IS INTENDED TO PROVIDE RATIONALE FOR EACH DENIED SERVICE WITHIN A REQUEST. REPEAT DD2, EITHER CHOICE 1 OR CHOICE 2, FOR EACH SERVICE DENIED BY VENDOR. FOR EACH SERVICE DENIED, DEPRECATE THE UNUSED ROW.]

CHOICE 1: [FOR POLICY DENIAL: DEPRECATE THIS ROW WHEN UNUSED]

[CODE] [SERVICE DECRIPTION]:

We denied the treatment, product or service your provider requested to treat your medical condition. Medicaid Health Plan policy rules found at [STATE SECTION AND GENERAL POLICY NAME HERE] guided our decision.

Here are the policy requirements your request did not meet:

[COMPLETE A BRIEF POLICY CITATION IN FREE TEXT. INCLUDE RELEVANT, BRIEF CLINICAL INFORMATION. USE COMPLETE SENTENCE FORMAT]

DD 2: **We denied the following services in your request.** [REPEAT DD2, EITHER CHOICE 1 OR CHOICE 2, FOR EACH SERVICE DENIED BY VENDOR]

CHOICE 2: [WHEN ADDITIONAL INFORMATION WAS REQUESTED AND NOT RECEIVED TIMELY: **DEPRECATE THIS ROW WHEN UNUSED**]

[CODE] [SERVICE DECRIPTION]: (repeat for each code to be addressed)

We asked your provider to send us more information about your request to help us approve it. Your provider didn't send us the information we requested.

- On [DATE OF REQUEST FOR ADDITIONAL INFORMATION], we asked your provider for the following important facts or documents: [BRIEF FREE TEXT STATEMENT ON ADDITIONAL INFORMATION REQUESTED].
- Without this additional information, your request did not meet criteria for approval found in [GENERAL POLICY NAME HERE].

DD 3: **North Carolina Medicaid does not cover the following service(s) in our State Medicaid Plan: [CODE] [SERVICE DESCRIPTION].**

8

Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) Benefit

The Medicaid benefit for its beneficiaries under 21 years of age is more robust than its coverage for adults, featuring assertive outreach, comprehensive preventive care and a broad menu of treatment services pinned to a developmental standard of medical necessity

Very important points to remember about the Medicaid benefit for children (EPSDT):

- Medicaid law at ***42 U.S.C. § 1396d(r) [1905(r) of the Social Security Act]***, requires states to provide to beneficiaries under 21 years *any* service listed in ***§ 1905(a)*** when an individualized review by federal criteria finds that service to be medically necessary to "*correct or ameliorate*" a health condition.
- Service(s) must be provided regardless of whether it is included in that state's menu of services and without regard to place of service or limits set by state policy.
- A request for a new or continuing service cannot be denied or reduced for a beneficiary under 21 years of age by state policy requirements or limits alone. Services may only be denied, reduced or stopped following a medical necessity review applying federal EPSDT criteria.

EPSDT Benefit and Pediatric *"Medical Necessity"*

The EPSDT Benefit and 'Services that Restore'

The Medicaid Act {CFR 440.130(d)} defines 'rehabilitative' (restorative) services as:

"Any medical or remedial service recommended by a physician or other clinical practitioner working within their scope of practice under state law, for the maximum *reduction* of physical or mental disability *and restoration* of an individual to the best possible functional level."

Remember the Basics!

- *The service does not have to 'cure' or completely restore an individual to a previous level of function.*
- *Services coverable by the EPSDT benefit must be 'medical in nature' but need not be included in either coverable policies, service definitions or billing codes posted by DMA or its agents.*

Adverse Benefit and Related Appeal Notices

EPSDT Review Rationales are Easy to Find and Clearly Written.

For beneficiaries under 21 years of age, further review under federal EPSDT criteria was completed. [INSERT VENDOR NAME] found the following federal EPSDT criteria unmet for your request:
[ADDRESS EACH DENIED REQUEST WITH ALL OF THE FOLLOWING OPTIONS THAT APPLY]

EPSDT Option 1: **The federal Medicaid program does not cover this service:** [CODE] [SERVICE DESCRIPTION] The service you've requested isn't included in Medicaid's coverable categories at §1905(a), Social Security Act.

EPSDT Option 2: **Your request is for an experimental or investigational treatment.** [CODE] [SERVICE DESCRIPTION] hasn't been approved in medical practice for the use intended by your provider. [PROVIDE BRIEF STATEMENT].

EPSDT Option 3: **The service requested isn't expected to help with (*"correct or ameliorate"* **) your medical condition.**

[CODE] [SERVICE DESCRIPTION]:

- Your provider didn't show that this service would be effective to help with your medical condition. [PROVIDE BRIEF EFFECTIVENESS or STANDARD OF CARE STATEMENT].
- There are equally effective and less costly treatments for your medical condition. [PROVIDE BRIEF STATEMENT ON OTHER TREATMENT(S)].
- This service hasn't been proven safe for treatment of your health condition. [PROVIDE BRIEF SAFETY STATEMENT].

**** For more information on EPSDT's 'correct or ameliorate' standard, see the 'EPSDT' section of this Notice.**

11

Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) Benefit

Future State Reports Will Monitor the EPSDT Benefit,

Age Group	Visits Completed Compliant with Early Periodic Screening AAP Standards	Visits Completed Compliant with Early Periodic Screening AAP Standards that Include At Least 1 Vaccine Administration	Total Preventive Service Visits (9938x and 9939x)	Visits Completed Compliant with Early Periodic Screening AAP Standards performed within 45 days of member request for appointment.	Screenings to caregivers for post-partum depression in member's first year of life. (CPT 96161)
Aged 1mo to 12 months					
Aged 12 through 23 Months					
Aged 24 through 35 Months					
aged 36 through 47 Months					
aged 48 through 59 Months					
aged 60 through 72 MontHs					
aged 6-9 years					
aged 10-14 years					
aged 15-18 years					
aged 19-20 years					

Age Group	ASD Specific Developmental Screens Completed (CPT 96110)	Emotional-Behavioral Screens Completed (CPT 96127)	Screening for Adolescent Depression Completed (CPT 96127)	Vision Screening Completed	Hearing Screening Completed	Adolescent Risk Screen (GAPS - HEADDS) Completed.
Aged 1mo to 12 months						
Aged 12 through 23 Months						
Aged 24 through 35 Months						
aged 36 through 47 Months						
aged 48 through 59 Months						
aged 60 through 72 MontHs						
aged 6-9 years						
aged 10-14 years						
aged 15-18 years						
aged 19-20 years						

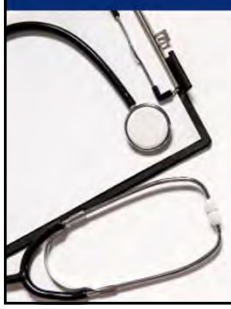
Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) Benefit

Future State Reports Will Monitor the EPSDT Benefit,

	Total Counts, Each Row				
Age Group	Requests for Prior Authorization	Requests for Prior Auth. Approved by Plan Policy	Requests for Prior Auth. Approved after EPSDTMedical Necessity Review	Requests for Prior Auth. Denied after EPSDT Medical Necessity Review	Requests for Prior Auth with 'Partial/Reduced Approvals' after EPSDT Medical Necessity Reviw
Aged 1mo to 12 months					
Aged 12 through 23 Months					
Aged 24 through 35 Months					
aged 36 through 47 Months					
aged 48 through 59 Months					
aged 60 through 72 MontHs					
aged 6-9 years					
aged 10-14 years					
aged 15-18 years					
aged 19-20 years					

EPSDT: Medicaid for Children

Lee James, Policy Analyst
Elizabeth Edwards, Senior Attorney



NATIONAL HEALTH LAW PROGRAM

About NHeLP

- National non-profit law firm committed to improving health care access and quality for underserved individuals and families
- State & Local Partners:
  - Disability rights advocates – 50 states + DC
  - Poverty & legal aid advocates – 50 states + DC
- National Partners
- Offices: CA, DC, NC
- www.healthlaw.org

2

Session Outline

- Medicaid Basics: EPSDT
- Focus on EPSDT, with emphasis on behavioral health
- Managed Care Transformation in North Carolina

3

Medicaid 101

- "Entitlement"
  - Covered population groups, *e.g.*
    - Children, pregnant women, aged, blind, disabled
  - Covered services, *e.g.*
    - Hospital, physician, home health, behavioral health
  - Due process notice and hearing rights if eligibility/services are denied/terminated

4

Why a Separate Benefit for Children & Youth with Disabilities?

- Family impact
  - Increase in single parent households
  - Increase in divorce
  - Increase in behavioral problems & academic failure of siblings
- Financial stress
  - 54% report family member stopped working
  - 45% report a family member cut back working
  - >20% report financial problems b/c of child's condition
- Caregiving stress
  - 58% report spending >40 hours per week providing support
  - 46% report more caregiving responsibilities than they can handle

5

Medicaid's Benefit for Children & Youth

E = Early

P = Periodic

S = Screening

D = Diagnostic

T = Treatment

6

EPSDT - A Guide for States:
Coverage in the Medicaid Benefit for Children and Adolescents

Available at: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html (June 2014)

7

EPSDT Requirements: Early and Periodic Screening

"Early identification of developmental disorders is critical to the well-being of children and their families. It is an integral function of the primary care medical home and an appropriate responsibility of all pediatric health care professionals."

AAP, *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An algorithm for Developmental Surveillance and Screening* (2006)

- EPSDT health and development assessment
  - Finding: providers using clinical judgment failed to identify 83% of children with a diagnosable behavioral health problem
  - NC: Formal developmental screening using scientifically validated tools such as: ASQ-3 (0-5 years), PEDS (up to age 8); PSC; SDQ; Bright Futures Adolescent; M-CHAT (R/F); STAT; HEADSSS; and GAPS

NC DMA, Health Check Program Guide (April 2018)

8

EPSDT Treatment Requirements

- States must arrange (directly or through referral) for corrective treatment needed as a result of a screen
  - Federal scope of benefits
  - Federal definition of medical necessity

9

Medicaid Scope of Benefits

Mandatory Services
Physician services
In-patient hospital
Laboratory/x-ray
Outpatient hospital
Nursing facility services
Home health care
Personal care services
Case management

Optional Services
Prescription drugs
Rehabilitation services
Physical, speech, & other therapies
Other licensed practitioners
Private duty nursing
Transportation

EPSDT: All necessary treatment within 1396d(a)

10

The Broad Nature of EPSDT

- Correct or ameliorate
  - "Services are covered when they prevent a condition from worsening or prevent development of additional health problems"
  - "*This is particularly important for children with disabilities, because such services can prevent conditions from worsening, reduce pain, and avert the development of more costly illnesses and conditions*."

CMS, *EPSDT – A GUIDE FOR STATES: COVERAGE IN THE MEDICAID BENEFIT FOR CHILDREN AND ADOLESCENTS* (June 2014)

11

North Carolina EPSDT

NC DMA, EPSDT Policy Instructions Update, at:

https://files.nc.gov/ncdma/documents/files/epsdtpolicyinstructions.pdf

NC DMA, EPSDT website, at:

https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services-right-you/medicaids-benefit-children-and-adolescents

12

EPSDT "Medical necessity"

- States may define, but "may not contradict or be more restrictive than the federal statutory requirement."
- Determinations must be made on a case-by-case basis
- States may place tentative limits on services, but **additional services must be provided if medically necessary for a child**
- Both the treating provider and the state play a role in determining medical necessity
  - Conflicts can be resolved by hearing

Source, CMS, *EPSDT — A Guide for States*

13

EPSD "T" Features

- Coverage of short-term & long-term services
- No waiting list for services
- No monetary cap on total cost
- No "hard" limit on number of hours or units
- No "hard" limit on number of MD, DDS, therapist, clinician visits
- No copayments for screening services

14

EPSD "T" Features: Federal EPSDT Criteria

- Service "fits within a Medicaid box"
- Necessary to correct or ameliorate the individual child's condition
- Safe and effective
- Not experimental
- No less costly, equally effective & available alternative in the geographic area
- May require prior authorization (15 business days)

15

EPSDT "Prior authorization"

- States may impose utilization controls
  - Ex.) Tentative limits on the amount of a treatment service a child can receive and require prior authorization for coverage of medically necessary services above those limits
  - Prior authorization cannot be required for EPSDT screening services

Source, CMS, *EPSDT: A Guide for States*

- Determination must be made on a case-by-case basis
- May not delay delivery of needed treatment services
- Must be consistent with the preventive thrust of EPSDT
- May consider the relative cost effectiveness of alternatives

Source, CMS, *EPSDT: A Guide for States*

16

EPSDT Settings

- Out-of-state services are NOT covered if medically necessary similarly efficacious services are available in state
- Services in schools can be covered, e.g., service provided through an IEP, basic health services such as vaccinations
- Most integrated setting appropriate, if necessary to comply with Title II of the ADA

17

EPSDT Settings: No Limits on Service Location

- Restrictions in clinical coverage policies or benefit plans must be waived if the services are necessary to correct or ameliorate, e.g.
  - Location of service
  - Prohibitions on multiple services on the same day
  - Prohibitions on multiple services at the same time

Ex.) A 13 year old who is getting Day Treatment may also get Intensive in Home if it is determined medically necessary. (EPSDT waives the service exclusion in the policy)

18

EPSDT Operational Principles

- Specific coverage criteria in the DMA clinical coverage policies or service definitions do **NOT have to be met** if the service is necessary to correct or ameliorate, *e.g.*
  - Particular diagnoses,
  - Particular signs or symptoms

Ex.) A 6 year old who is displaying psychotic features who has never had any lower level of services and who is not at risk for out of home placement can still get Intensive in Home if medical necessity is met.

19

EPSDT Available to HCBS Waiver Recipients

- Additional services can be offered through waivers
  - Respite, home modifications
  - Not covered by EPSDT mandate
  - Waiver services are supposed to complement state plan/EPSDT services
- Children enrolled in CAP/C or the Innovations Waiver can receive BOTH Waiver and EPSDT services.

20

EPSDT Informing Requirements

- States must inform Medicaid families & children about EPSDT
- Informing must be effective
  - Oral and written
  - Translated for Limited English Proficiency (LEP)
  - Accessible for hearing/vision impaired
  - Targeted (e.g. pregnant teens, non-users)
- Transportation & appointment scheduling assistance(prior to due date of each periodic screen)
- Coordinate with other entities

21

EPSDT Benefits in North Carolina

- NC Framing: 2 Kinds of EPSDT Benefits
  - Extensions or modifications of benefits that are listed in the State Plan. EPSDT requires the limits in the service definition be modified if medically necessary to treat or ameliorate a condition.
    - Getting Day Treatment at the same time as Intensive in Home
    - Getting Community Networking and Intensive in Home
  - A child may need a service that is NOT listed in the North Carolina State Medicaid Plan **but coverable** under federal Medicaid law, 1396d(a) of the SSA for recipients under 21 years of age. This requested service is called a "Non-Covered State Medicaid Plan Service."
    - ABA

22

What to Include in the Request

- Documentation for a service under the EPSDT Medicaid provision should show how the service will correct or ameliorate a defect, physical or mental illness or a condition
- Show how the service meets the EPSDT requirements
  - safe, effective, not experimental and medically necessary to correct or ameliorate the condition or illness
- You may use additional sheets to supply any other information you think would be helpful
- Include evidence-based literature, if available

23

What to Include in the Request

- Clinicians should describe the individual's condition, their need for services, alternatives that have been tried and/or reject, and explain how the service will correct or ameliorate the child's condition

24

The EPSDT Review Process

- The determination of whether a service is medically necessary for an individual child must be made on a case-by-case basis
- The MCO should consider the child's long-term needs, not just what is required to address the immediate situation. The MCO should consider all aspects of a child's needs.
- Services are covered when they have an ameliorative, maintenance purpose

SOURCE, CMS, *EPSDT – A GUIDE FOR STATES*

25

NC Medicaid Transformation

- North Carolina 1115 waiver
  - Transition to Medicaid managed care
  - Statewide commercial plans, provider-led entities, tailored plans
- EPSDT behavioral health services
  - Covered by Standard Plans to children under age 21 who require a service
  - Tailored Plans – broad target population for children

26

Managed Care Concerns

- Lack of information re: covered services & rights
- Inadequate networks
- Poor dispute resolution

27

Questions?
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| 28

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

Equal Access to Healthcare for Individuals with Disabilities

Contents

- PowerPoint Presentation Handout

Equal Access To Health Care Services For Individuals With Disabilities

Cassie L. Crawford
Assistant United States Attorney
Affirmative Civil Enforcement
USAO Middle District of North Carolina

Disclaimer

Opinions Expressed Herein or Otherwise are those of the Speaker and do not Necessarily Reflect the Views of the United States Department of Justice.

2

Overview

1. DOJ Enforcement and the Barrier-Free Health Care Initiative
2. Effective communication for individuals who are deaf or hard of hearing
3. Equal access for individuals with HIV/AIDS
4. Physical access for individuals who have a mobility impairment
5. How to report discrimination

3

What Is Covered By ADA?

The ADA prohibits discrimination and ensures equal opportunities for persons with disabilities in:

- Employment (Title I)
- State and local government services (Title II)
- Public accommodations (Title III)

4

Title III Covers Private Sector Hospitals, Nursing Homes and Other Health Care Providers

Title III covers "public accommodations," which include a wide range of entities, such as:
(1) Hospitals;
(2) Professional offices of health care providers; and
(3) Nursing homes.

42 U.S.C. § 12181(7)(F) & (K); ADA Technical Assistance Manual, § III-1.2000.C (1994 Supplement). ("Nursing homes are expressly covered in Title III regulations as social service establishments."). https://www.ada.gov/taman3up.html

5

ADA : DOJ Enforcement

- Department of Justice has authority:
  - To investigate alleged ADA violations;
  - To undertake compliance reviews;
  - To file a lawsuit if:
    - Pattern or practice of discrimination, or
    - Issue of general public importance.

ADA Enforcement & Remedies

- Injunctive Relief (e.g., establishing new policies and procedures, and training)
- Compensatory Damages (actual damages and pain and suffering)
- Civil Penalty

42 U.S.C. § 12188.

7

Important ADA Resource: ADA.gov

8

Barrier-Free Health Care Initiative

Through the Barrier-Free Health Care Initiative, U.S. Attorneys' offices and DOJ's Civil Rights Division are targeting their enforcement efforts on access to medical services and facilities:

(1) Effective communication for people who are deaf or have hearing loss;

(2) Equal access to treatment for people who have HIV/AIDS; and

(3) Physical access to medical care for people with mobility disabilities.

9

Effective Communication

Health Care Providers Must Furnish Auxiliary Aids

- No individual can be excluded, denied services, or otherwise treated differently because of the absence of auxiliary aids or services. 42 U.S.C. § 12182(a) (ADA); 28 C.F.R. § 36.303(a) (ADA regulations)
- Covered entities must furnish appropriate auxiliary aids and services where necessary for effective communication. 28 C.F.R. § 36.303(c)

Effective Communication

- Entities must ensure that communication with people with disabilities is as effective as communication with others.
- The type of auxiliary aid needed will **vary by context and depends on many factors:**

1. What is the **method of communication** used by the individual? (e.g., ASL, signed English, oral interpreter)
2. How **lengthy** is the communication?
3. How **complex** is the communication?
4. What is the **nature** of the communication?

Individual Assessment Is Important

The ADA regulations state that a health care provider should conduct an assessment of each individual with a communication related disability to determine the type of auxiliary aid that is appropriate. 28 C.F.R. § 36.303(c)(1)(ii).

Regulations define "auxiliary aids and services" to include many types of aids and services, including qualified interpreters (either in person or through VRI), CapTel phones, videophones, real-time captioning, hearing-aid compatible telephones, etc. **The auxiliary aid must be EFFECTIVE for the individual.**

13

Length/Complexity/Nature of Communication (ADA Business Brief)

- Situations where an interpreter may be required for effective communication:
  - Discussing a patient's symptoms and medical condition, medications, and medical history
  - Explaining and describing medical conditions, tests, treatment options, medications, surgery and other procedures
  - Providing a diagnosis, prognosis, and recommendation for treatment
  - Obtaining informed consent for treatment
  - Communicating with a patient during treatment, testing procedures, and during physician's rounds

14

ADA Business Brief: Communicating with People Who Are Deaf or Hard of Hearing in Hospital Settings

- Situations where an interpreter may be required for effective communication (continued):
  - Providing instructions for medications, post-treatment activities, and follow-up treatments
  - Providing mental health services, including group or individual therapy, or counseling for patients and family members
  - Providing information about blood or organ donations
  - Explaining living wills and powers of attorney
  - Discussing complex billing or insurance matters
  - Making education presentations, such as birthing and new parent classes, nutrition and weight management counseling, and CPR and first aid training

15

In Addition, In Order to be Effective…

Video Remote Interpreting (VRI) must have:

1. Real-time video and audio with high quality images (no lags, grainy images, irregular pauses)
2. Sufficient dedicated high-speed, wide-bandwidth connection
3. Large enough screen
4. Clear voices
5. Staff trained for quick set-up and proper operation.

28 C.F.R. § 36.303(f)

16

In Addition, In Order to be Effective…

"**Qualified Interpreter**" must be able to interpret:

1. **Effectively**
2. **Accurately**
3. **Impartially**
4. Understanding the necessary **specialized vocabulary** that is used for the particular setting (*e.g.*, medical settings).

28 C.F.R. § 36.104; *see also* Technical Assistance Manual, § III-4.3200.

17

ADA Prohibition On Relying Upon Companions To Facilitate Communication

A provider **shall not** rely on an adult accompanying an individual with a disability to interpret . . .except –

- In an emergency involving an **imminent threat** to the safety or welfare of an individual or the public where there is not an interpreter available; or
- Where the individual with a disability **specifically requests** that the accompanying adult interpret or facilitate communication, the accompanying **adult agrees** to provide such assistance, and reliance on that adult for such assistance is **appropriate under the circumstances**.

"A public accommodation **shall not** rely on a minor child to interpret or facilitate communication, except in an emergency involving an imminent threat to the safety or welfare of an individual or the public where there is no interpreter available."

28 C.F.R. § 36.303(c)(3) & (4).

18

ADA's Effective Communication Requirement Covers Patients and "Companions"

The ADA regulations require public accommodations to furnish auxiliary aids and services to "individuals with disabilities" and "companions who are individuals with disabilities." 28 C.F.R. § 36.303(c).

"**Effective communication with companions** is particularly critical in **health care settings** where miscommunication may lead to misdiagnosis and improper or delayed medical treatment."

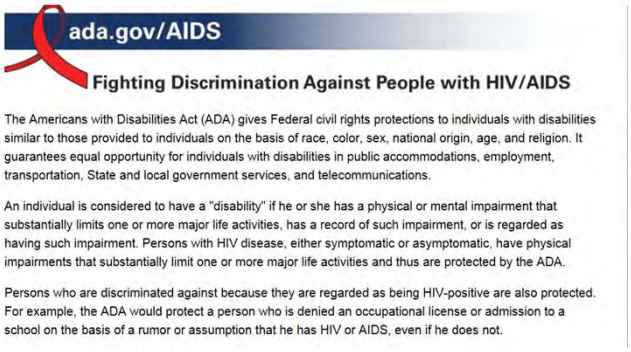
- 28 C.F.R. part 36, Appendix A (emphasis added).

19

DOJ Enforcement (Auxiliary Aids): Examples

- *Floyd Medical Center (Rome, GA)*. Failure to provide interpreter or functional VRI (including in connection with complicated labor; emergency care).
  - Settlement Agreement included damages for complainants, plus broad equitable relief: compliance requirements (e.g., timing requirements for providing interpreter; functionality requirements for VRI, notice and training to staff and physicians, appointing ADA Administrator.
- *Assoc. Foot and Ankle Centers of Northern Virginia.* Failure to provide interpreter during multiple appointments, including pre- and post-surgery.
  - Similar settlement to above: use of "communication assessment" form; conspicuously labeling medical charts; contract with interpreter; limitations on using VRI (inability to move head, significant pain, etc).

Equal access to treatment for people who have HIV/AIDS



ada.gov/AIDS

Fighting Discrimination Against People with HIV/AIDS

The Americans with Disabilities Act (ADA) gives Federal civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications.

An individual is considered to have a "disability" if he or she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such impairment. Persons with HIV disease, either symptomatic or asymptomatic, have physical impairments that substantially limit one or more major life activities and thus are protected by the ADA.

Persons who are discriminated against because they are regarded as being HIV-positive are also protected. For example, the ADA would protect a person who is denied an occupational license or admission to a school on the basis of a rumor or assumption that he has HIV or AIDS, even if he does not.

The ADA Covers Individuals With HIV or AIDS

The ADA covers impairments to major bodily functions such as the immune system. 42 U.S.C. § 12102 (2)(B). The ADA protects individual with HIV or AIDS, whether they are symptomatic or asymptomatic.

22

ADA Mandates Equal Treatment By Health Care Providers For Individuals With HIV or AIDS

Individuals with HIV or AIDS are entitled to **equal treatment** by health care providers. As with other disabilities, the ADA prohibits public accommodations from excluding, denying services, or otherwise treating an individual differently due to a disability. 42 U.S.C. § 12182(a) (ADA); 28 C.F.R. § 36.303(a).

23

ADA Prohibits A Health Care Provider From Refusing To Treat A Patient Simply Because She Has HIV

First, there are little to no circumstances in which a person with HIV would pose a direct threat to the health or safety of others. Health care providers are required to treat all persons as if they have blood-borne pathogens, and must use universal precautions (gloves, mask, and/or gown where appropriate, etc.). Failure to treat a person who discloses that she has HIV out of a fear of contracting HIV would be a violation of the ADA.

24

ADA Prohibits A Health Care Provider From Refusing To Treat A Patient Simply Because She Has HIV

Second, a health care provider cannot refer a patient with HIV or AIDS to another provider simply because the patient has HIV or AIDS.

The referral must be based on the fact that the treatment the patient is seeking is outside the expertise of the provider, not the patient's HIV status alone.

25

Q&A: The ADA and Persons with HIV/AIDS

- An individual with HIV has a severe allergic drug reaction while on vacation and goes to the nearest emergency room. The hospital routinely treats people experiencing allergic drug reactions. Sending the patient to another hospital that allegedly has an "AIDS unit" would violate the ADA.
- An individual with HIV is in a car accident and suffers severe third degree burns. He is taken to the nearest hospital, which does not have a burn unit. Sending the patient to another hospital that has a burn unit would not violate the ADA.
  - https://www.ada.gov/hiv/ada_q&a_hiv.pdf

DOJ Enforcement (HIV/AIDS): Examples

North Florida OB/GYN Assocs. Refusal to schedule elective tubal ligation for patient because she had HIV. Settlement required practice to adopt a non-discrimination policy, train employees, pay compensatory damages.

Rite Aid of Michigan. Pharmacist refused to administer a flu shot to individual with HIV. Settlement required Rite Aid to pay compensatory damages and civil penalty, adopt a non-discrimination policy, implement required training for employees.

Physical access to medical care for people with mobility disabilities

Access To Medical Care For Individuals With Mobility Disabilities

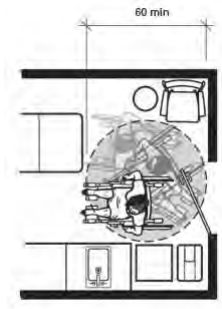
Physical accessibility of doctors' offices, clinics, and other health care providers is essential in providing medical care to people with disabilities.

Due to physical barriers, individuals with disabilities are less likely to get routine preventative medical care than people without disabilities.

Accessibility is not only legally required by the ADA and Rehab Act, it is important medically so that minor problems can be detected and treated before turning into major and possibly life-threatening problems.

29

DOJ Technical Assistance for Providers



Plan view of part of an examination room showing clear floor space for turning a wheelchair. This space can also make it possible for use of a portable patient lift.

An adjustable height exam table shown in lowered and raised positions

30

Common Questions (from DOJ Publication)

- Is it OK to examine a patient who uses a wheelchair in the wheelchair, because the patient cannot get onto the exam table independently?
  - **Generally no.**
- Can I tell a patient that I cannot treat her because I don't have accessible medical equipment?
  - **Generally no.**
- Is it OK to tell a patient who has a disability to bring along someone who can help at the exam?
  - **No.**

31

Common Questions (from DOJ Publication)

- Can I decide not to treat a patient with a disability because it takes me longer to examine them, and insurance won't reimburse me for the additional time?
  - **No, you cannot refuse to treat a patient who has a disability just because the exam might take more of your or your staff's time.**
- Must <u>every</u> examination room have an accessible exam table and sufficient clear floor space next to the exam table?
  - **Probably not.**

32

DOJ Enforcement (Accessible Medical Equipment): Examples

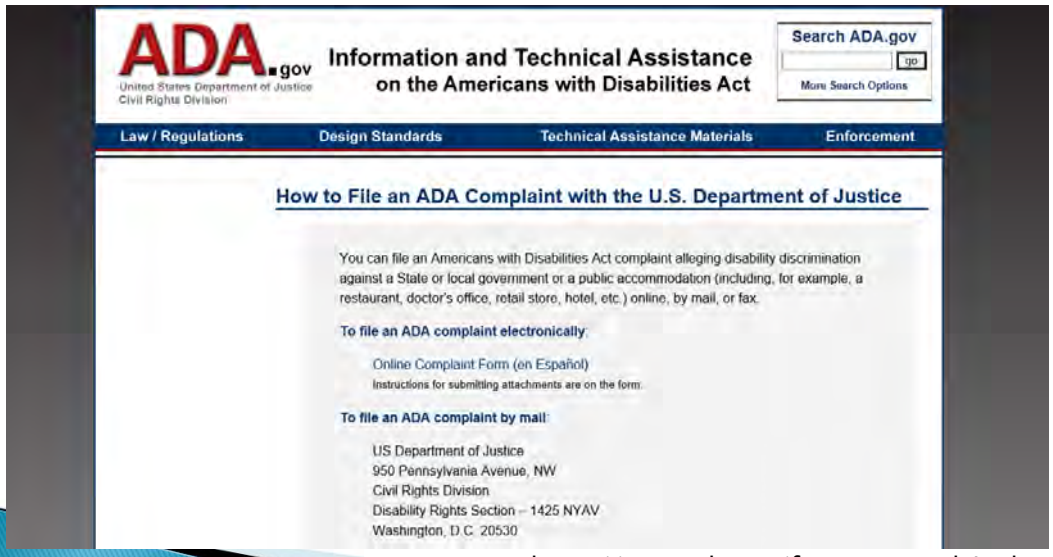
Charlotte Radiology, P.A. Practice refused to perform bone density test on complainant who has parapalegia and uses a wheelchair, unless the patient brought someone to assist in transferring her to DEXA machine. (Per policy, staff would not transfer patients.) Required to adopt non-discrimination policy, train staff, purchase or lease 2 patient lifts; remove architectural barriers.

Marin Magnetic Imaging. Technicians refused to transfer a patient, who has quadrapalegia and uses a wheelchair, to the MRI table. Equitable relief as above, including the purchase of a MRI compatible adjustable gurney.

33

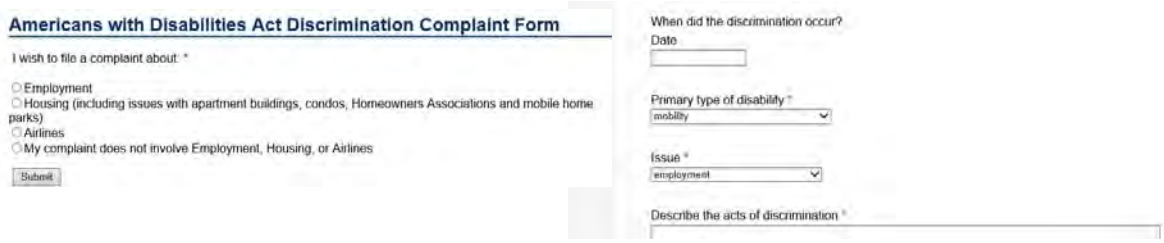
Reporting Discrimination

Reporting on ADA.gov



https://www.ada.gov/fact_on_complaint.htm

Reporting on ADA.gov



https://www.ada.gov/complaint/

3. What accommodations may I request if I cannot prepare my own ADA complaint because of my disability?

If you are unable to write because of your disability and are unable to submit a complaint online, by mail, or fax, the Department can assist you by scribing your complaint by phone or, for individuals who communicate by American Sign Language, by videophone.

Contact the ADA Information Line at 1-800-514-0301 (voice) or 1-800-514-0383 (TTY) to schedule an appointment. Please be advised that it may take two weeks or more for Department staff to contact you.

Reporting ADA Issues in MDNC

(in addition to ADA.gov reporting)

USANCM.CivilRights@usdoj.gov

Surry, Stokes, Rockingham, Caswell, Person, Yadkin, Davie, Forsyth, Guilford, Alamance, Orange, Durham, Rowan, Davidson, Randolph, Chatham, Cabarrus, Stanly, Montgomery, Moore, Lee, Richmond, Scotland, Hoke

MIDDLE DISTRICT OF NORTH CAROLINA
UNITED STATES ATTORNEYS OFFICE

37

Equal Access to Health Care- Systemic Litigation Update

DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

This document contains general information for educational purposes and should not be construed as legal advice. It is not intended to be a comprehensive statement of the law and may not reflect recent legal developments.

38

Bone v. UNC Health Care Systems

- Federal Complaint Filed in the Middle District of North Carolina last December
- Defendants: UNC Health Care and Nash Hospital Inc.
- Plaintiffs: Two Blind Health Care Patients, National Federation of the Blind, and Disability Rights North Carolina
- Summary of Alleged Facts

Bone v. UNC Health Care Systems

Legal Allegations

- ADA, Section 504, and the ACA all require defendants and their contractors to provide appropriate auxiliary aids and services, such as Braille and large print, to blind patients to ensure effective communication
- Defendants are responsible for ensuring its contractors comply with the ADA, Section 504, and the ACA
- UNC, Nash, and their contractors are only providing critical communications, such as health care notices, visit summaries, follow-up instructions, forms, questionnaires, invoices, in standard print.

Bone v. UNC Health Care Systems

Relief Requested

- Declare that Defendants are not providing equal access to health information for blind patients
- Require Defendants to develop and implement a comprehensive accessibility policy to ensure equal access to health care information for blind patients
- Award compensatory damages and attorney fees

Bone v. UNC Health Care Systems

Both Defendants have asked the court to dismiss the case. The motions are not yet resolved. Important issues before the court:

- Who is responsible for effective communication injuries in a health care setting?
- What does deliberate indifference look like in a health care setting?
- What steps do health care providers have to take to prevent effective communication violations from recurring?

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

Ethical Considerations: Representing Clients with Disabilities

Contents

- PowerPoint Presentation Handout
- N.C. State Bar Rule of Professional Conduct 1.14
- N.C. State Bar Rule of Professional Conduct 1.6
- N.C. State Bar Ethics Opinion 157
- Effective Communication and the ADA
- N.C. Gen. Stat. § 122C-3

DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

Clients with Diminished Capacity: Ethical Considerations

Disability Advocacy Conference – May, 1, 2019

Kristine Sullivan, Supervising Attorney

Terminology

Intellectual Disability

- Present from childhood
- Cognitive capacity (IQ) and adaptive functioning
- Severity determined by adaptive functioning

Mental Illness

- Wide variety of conditions that may interfere with occupational, social and daily functions
- Not tied to IQ or age
- May be temporary, cyclical or episodic

4

Developmental Disabilities

- Severe and chronic; likely to continue indefinitely
- Caused by mental and/or physical impairment
- Manifested before age 22 (exception: head injuries)
- Results in substantial functional limitations in 3 or more of major life activities listed in statute

5

Physical, Sensory and Neurological Disabilities

- Orthopedic impairments
- Deaf/hard-of-hearing
- Blind/low vision
- Spinal cord injury
- Traumatic Brain Injury
- Epilepsy
- Diabetes
- Cerebral palsy
- Dementia

6

Substance Use Disorder

- Presence of at least 2 of 11 criteria
- Severity determined by number of criteria
- Specific substance addressed as separate use disorder (e.g. alcohol use disorder)

7

If a client doesn't self-identify you may need to assess:

- Does the client act or talk in a different manner?
- Does the client seem unusually confused or preoccupied?
- Is the client's speech hard to understand?
- Does the client's vocabulary seem limited?
- Does the client have difficulty expressing him/herself?

8

History Questions

- Did you attend special classes in school?
- Have you ever received Mental Health or DD services?
- Do you get any kind of social security check?
- Is there a guardian, rep payee, or POA who helps with your finances or decisions?

9

Person-First Language

- Put the person *before* the disability
- Describe what a person *has*, not who a person *is*
- Reframe “problems” into “needs”

10

Examples

Say . . .	Instead of . . . .
Child / adult with disability	Handicapped or disabled
She has autism.	She’s autistic.
He has an intellectual disability.	He’s mentally retarded.
She uses a wheelchair.	She’s wheelchair-bound.
Congenital disability / Brain injury	Birth defect / Brain damage
Accessible parking	Handicapped parking

11

Attorney-Client Relationship

12

Rule 1.14(a)

- When a client's capacity to make "adequately considered decisions" in connection with a representation is diminished, the lawyer shall, as far as reasonably possible, maintain a "normal" relationship with the client

13

Commentary suggests reasons Rule 1.14 was needed

- Clients with disabilities may be unable to monitor their attorneys' performance.
- Studies found that attorneys spend less time interviewing clients with disabilities than other clients.
- There is a tendency to usurp decisions that should be left to the client.

14

"Normal" Client Relationship

- Effective communication
- Duty of loyalty to client, not guardian
- When necessary to assist in representation, presence of third person does not affect applicability of attorney-client privilege.

15

Taking Protective Action

16

Rule 1.14(b)

- May take protective action if reasonably believe:
  - Client has diminished capacity;
  - Client is at risk of substantial physical, financial or other harm unless action is taken; and
  - Client cannot adequately act in own interest

17

Examples

- Consulting with family members
- Consulting with professionals and/or adult protective services
- Alternatives to guardianship
- Appointment of GAL or guardian

18

Factors to Consider

- Client's wishes and values, to the extent known
- Client's best interests
- Preserving client's decision-making autonomy to the greatest extent feasible
- Maximizing client's capabilities
- Respecting the client's family and social connections

19

Confidentiality of Information

- Rule 1.6(a): shall not reveal information unless client gives informed consent, disclosure implicitly authorized to carry out representation, or permitted by Rule
- Rule 1.14(c): when taking protective action, lawyer is implicitly authorized to reveal information under Rule 1.6(a) only to extent reasonably necessary to protect client's interests

20

Effective Communication

21

Rule 1.4: Lawyer shall

- Promptly notify client of decision or circumstance that requires informed consent
- Reasonably consult with client about means to accomplish objectives
- Keep client reasonably informed about status of matter
- Respond to reasonable requests for information
- Consult about limitation on lawyer's conduct

22

More Rule 1.4: Lawyer shall

- "Explain a matter to the extent reasonably necessary to permit the client to make informed decisions regarding the representation"

23

Effective Communication: General Tips

- Learn about client's disability
- Ask about needs and preferences
- Talk to client
- Be aware of body language
- Patience, humor and the Golden Rule

24

Effective Communication: Client with ID

- Limit distractions, people present
- Begin by asking some basic questions to assess level of basic knowledge
- Ask questions a number of ways; ask the person to repeat or explain statements
- Avoid compound or complex sentences

25

More Communication: Client with ID

- Wait for a response before continuing
- Eye contact
- Concrete, not abstract
- Minimize and simplify written information

26

Effective Communication: Client with MI

- Be aware of possible processing difficulties
- Be aware of body language
- Wait for a response before continuing
- Let the person know you are prepared to believe them

27

Effective Communication: Client with Dementia

- Limit distractions
- Avoid compound or complex sentences
- Be aware of processing difficulties
- Ask yes/no questions
- Ask questions a number of ways

28

More Communication: Client with Dementia

- Do not confront untruths; work around them
- Don’t finish sentence or find word unless asked
- Behavior is communication
- Have discussions earlier in the day

29

The Americans with Disabilities Act

30

Equal Access to Legal Services

- Prohibits discrimination on the basis of disability in any place of public accommodation -- including lawyer's office
- Discrimination includes failure to make reasonable modifications unless modification is fundamental alteration

31

ADA & Effective Communication

- Public accommodation shall furnish appropriate auxiliary aids and services where necessary to ensure effective communication
- If particular aid or service would result in fundamental alteration or undue burden, the public accommodation must provide an alternative aid or service (if one exists)

32

Effective Communication

- Meaningful, two-way communication
  - Qualified interpreter
  - "Companion interpreter"
  - Relay services and Video Remote Interpreting (VRI)

33

Effective Communication

- Fundamental alteration
- Undue burden
- Must provide alternative aid or service if exists

34

ADA & Effective Communication

- Must also provide auxiliary aids and services to companions with disabilities
- Should consult with individual to determine what type of auxiliary aid is needed to ensure effective communication (but ultimate decision rests with public accommodation)

35

Examples: Auxiliary Aids & Services

- Note-takers
- Real-time computer-aided transcription services
- Large print
- Text-to-speech technology
- Telephones compatible with hearing aids
- Video text displays
- TTYs or videophones
- Screen reader or magnifier

36

Service Animals

- Individually trained to do work or perform tasks directly related to disability
- May exclude if fundamental alteration
  - Not allergies or fear
- If exclude, still have to offer services

37

DOJ Enforces Equal Access

- 2010 Consent Decree with Colorado attorney
  - Adopt an ADA-compliant service animal policy and post in conspicuous location;
  - Post a “Service Animals Welcome” sign;
  - Undergo training and provide training to staff; and
  - Pay $50,000 in fees and penalties.

http://www.ada.gov/lehouillier.htm

38

Contact Information

Disability Rights North Carolina
North Carolina’s Protection and Advocacy System
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39

CLIENT-LAWYER RELATIONSHIP

Search Rules

RULE 1.14 CLIENT WITH DIMINISHED CAPACITY

(a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

(b) When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken and cannot adequately act in the client's own interest, the lawyer may take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem or guardian.

(c) Information relating to the representation of a client with diminished capacity is protected by Rule 1.6. When taking protective action pursuant to paragraph (b), the lawyer is impliedly authorized under Rule 1.6(a) to reveal information about the client, but only to the extent reasonably necessary to protect the client's interests.

Comment

[1] The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. When the client is a minor or suffers from a diminished mental capacity, however, maintaining the ordinary client-lawyer relationship may not be possible in all respects. In particular, a severely incapacitated person may have no power to make legally binding decisions. Nevertheless, a client with diminished capacity often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being. For example, children as young as five or six years of age, and certainly those of ten or twelve, are regarded as having opinions that are entitled to weight in legal proceedings concerning their custody. So also, it is recognized that some persons of advanced age can be quite capable of handling routine financial matters while needing special legal protection concerning major transactions.

[2] The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client with attention and respect. Even if the person has a legal representative, the lawyer should as far as possible accord the represented person the status of client, particularly in maintaining communication.

[3] The client may wish to have family members or other persons participate in discussions with the lawyer. When necessary to assist in the representation, the presence of such persons generally does not affect the applicability of the attorney-client evidentiary privilege. Nevertheless, the lawyer must keep the client's interests foremost and, except for protective action authorized under paragraph (b), must to look to the client, and not family members, to make decisions on the client's behalf.

[4] If a legal representative has already been appointed for the client, the lawyer should ordinarily look to the representative for decisions on behalf of the client. In matters involving a minor, whether the lawyer should look to the parents as natural guardians may depend on the type of proceeding or matter in which the lawyer is representing the minor. If the lawyer represents the guardian as distinct from the ward, and is aware that the guardian is acting adversely to the ward's interest, the lawyer may have an obligation to prevent or rectify the guardian's misconduct. See Rule 1.2(d).

Taking Protective Action

[5] If a lawyer reasonably believes that a client is at risk of substantial physical, financial or other harm unless action is taken, and that a normal client-lawyer relationship cannot be maintained as provided in paragraph (a) because the client lacks sufficient capacity to communicate or to make adequately considered decisions in connection with the representation, then paragraph (b) permits the lawyer to take protective measures deemed necessary. Such measures could include: consulting with family members, using a reconsideration period to permit clarification or improvement of circumstances, using voluntary surrogate decision-making tools such as durable powers of attorney or consulting with support groups, professional services, adult-protective agencies or other individuals or entities that have the ability to protect the client. In taking any protective action, the lawyer should be guided by such factors as the wishes and values of the client to the extent known, the client's best interests and the goals of intruding into the client's decision-making autonomy to the least extent feasible, maximizing client capacities and respecting the client's family and social connections.

CLIENT-LAWYER RELATIONSHIP

Search Rules

RULE 1.6 CONFIDENTIALITY OF INFORMATION

(a) A lawyer shall not reveal information acquired during the professional relationship with a client unless the client gives informed consent, the disclosure is impliedly authorized in order to carry out the representation or the disclosure is permitted by paragraph (b).

(b) A lawyer may reveal information protected from disclosure by paragraph (a) to the extent the lawyer reasonably believes necessary:

(1) to comply with the Rules of Professional Conduct, the law or court order;

(2) to prevent the commission of a crime by the client;

(3) to prevent reasonably certain death or bodily harm;

(4) to prevent, mitigate, or rectify the consequences of a client's criminal or fraudulent act in the commission of which the lawyer's services were used;

(5) to secure legal advice about the lawyer's compliance with these Rules;

(6) to establish a claim or defense on behalf of the lawyer in a controversy between the lawyer and the client; to establish a defense to a criminal charge or civil claim against the lawyer based upon conduct in which the client was involved; or to respond to allegations in any proceeding concerning the lawyer's representation of the client;

(7) to comply with the rules of a lawyers' or judges' assistance program approved by the North Carolina State Bar or the North Carolina Supreme Court; or

(8) to detect and resolve conflicts of interest arising from the lawyer's change of employment or from changes in the composition or ownership of a firm, but only if the revealed information would not compromise the attorney-client privilege or otherwise prejudice the client.

(c) A lawyer shall make reasonable efforts to prevent the inadvertent or unauthorized disclosure of, or unauthorized access to, information relating to the representation of a client.

(d) The duty of confidentiality described in this Rule encompasses information received by a lawyer then acting as an agent of a lawyers' or judges' assistance program approved by the North Carolina State Bar or the North Carolina Supreme Court regarding another lawyer or judge seeking assistance or to whom assistance is being offered. For the purposes of this Rule, "client" refers to lawyers seeking assistance from lawyers' or judges' assistance programs approved by the North Carolina State Bar or the North Carolina Supreme Court.

Comment

[1] This Rule governs the disclosure by a lawyer of information relating to the representation of a client acquired during the lawyer's representation of the client. See Rule 1.18 for the lawyer's duties with respect to information provided to the lawyer by a prospective client, Rule 1.9(c)(2) for the lawyer's duty not to reveal information acquired during a lawyer's prior representation of a former client, and Rules 1.8(b) and 1.9(c)(1) for the lawyer's duties with respect to the use of such information to the disadvantage of clients and former clients and Rule 8.6 for a lawyer's duty to disclose information to rectify a wrongful conviction.

[2] A fundamental principle in the client-lawyer relationship is that, in the absence of the client's informed consent, the lawyer must not reveal information acquired during the representation. See Rule 1.0(f) for the definition of informed consent. This contributes to the trust that is the hallmark of the client-lawyer relationship. The client is thereby encouraged to seek legal assistance and to communicate fully and frankly with the lawyer even as to embarrassing or legally damaging subject matter. The lawyer needs this information to represent the client effectively and, if necessary, to advise the client to refrain from wrongful conduct. Almost without exception, clients come to lawyers in order to determine their rights and what is, in the complex of laws and regulations, deemed to be legal and correct. Based upon experience, lawyers know that almost all clients follow the advice given, and the law is upheld.

[3] The principle of client-lawyer confidentiality is given effect by related bodies of law: the attorney-client privilege, the work product doctrine and the rule of confidentiality established in professional ethics. The attorney-client privilege and work-product doctrine apply in judicial and other proceedings in which a lawyer may be called as a witness or otherwise required to produce evidence concerning a client. The rule of client-lawyer confidentiality applies in situations other than those where evidence is sought from the lawyer through

RPC 157

Search Adopted Opinions

REPRESENTING A CLIENT OF QUESTIONABLE COMPETENCE

Adopted: April 16, 1993

Opinion rules that a lawyer may seek the appointment of a guardian for a client the lawyer believes to be incompetent over the client's objection.

Editor's Note: See Rule 1.14 of the Revised Rules for additional guidance.

Inquiry #1:

Attorney A represents a client on a social security matter and determines, from confidential communications with his client, that the client is, in the attorney's opinion, not competent to handle his affairs in relation to the representation and that the client's actions in regard to the matters involved in the representation are detrimental to the client's own interest. For example, the client who sought the attorney's assistance with receipt of benefits from the social security administration, refuses to cash checks obtained for the client from social security despite the client's obvious need for financial support. The attorney believes that either a guardian should be appointed for the client under state law or that a representative payee should be appointed for the client under federal social security law. The client refuses to agree for the attorney to seek the appointment of a guardian, to seek the appointment of a representative payee, or even for the attorney to discuss this problem with the client's family. The attorney is of the opinion that the client lacks the capacity to form objectives necessary for a normal attorney/client relationship.

May the attorney seek the appointment of a guardian or a representative payee for the client?

Opinion #1:

Yes. The Rules of Professional Conduct do not speak directly to the question presented. There is language in the comment to Rule 2.8 concerning discharge and withdrawal suggesting that where an attorney is representing a client who is mentally incompetent she may "in an extreme case... initiate proceedings for a conservatorship or similar protection of the client." It follows that Attorney A may under the circumstances described seek the appointment of a guardian or a representative payee without the client's consent and over the client's objection if such appears to be reasonably necessary to protect the client's interests. In so doing, the attorney may disclose only her belief that there exists a good faith basis for the relief requested and may not disclose the confidential information which led her to conclude that the client is incompetent, except as permitted or required by Rule 4(c).

Inquiry #2:

In taking that action, may the attorney reveal confidential information so as to establish the grounds for guardianship or representative payee status?

Opinion #2:

See the answer to Inquiry #1.

Inquiry #3:

If the attorney may not seek appointment of a representative payee or guardian, must the attorney withdraw from the matter?

Opinion #3:

See the answer to Inquiry #1.

Effective Communication and the ADA

No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation [which includes the office of a lawyer] by any person who owns, leases (or leases to), or operates a place of public accommodation. 42 U.S.C. §§ 12182(a), 12181(7)(F); 28 C.F.R. § 36.104.

Discrimination includes failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations. 42 U.S.C. § 12182(b)(2)(A)(ii).

A public accommodation shall furnish appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities. 28 C.F.R. § 36.303(c).

If provision of a particular auxiliary aid or service by a public accommodation would result in a fundamental alteration or in an undue burden, the public accommodation shall provide an alternative auxiliary aid or service, if one exists, that would ensure that, to the maximum extent possible, individuals with disabilities receive the goods, services, facilities, privileges, advantages, or accommodations offered by the public accommodation. 28 C.F.R. § 36.303(f).

§ 122C-3. Definitions.

The following definitions apply in this Chapter:

. . .

(12a) "Developmental disability" means a severe, chronic disability of a person which:

a. Is attributable to a mental or physical impairment or combination of mental and physical impairments;

b. Is manifested before the person attains age 22, unless the disability is caused by a traumatic head injury and is manifested after age 22;

c. Is likely to continue indefinitely;

d. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction and economic self-sufficiency; and

e. Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated; or

f. When applied to children from birth through four years of age, may be evidenced as a developmental delay.

. . .

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Disability Advocacy Conference
May 1, 2019

Guardianship Reform in North Carolina

Contents

- General Assembly of North Carolina Session 2019 House Bill 619

HOUSE BILL 619*

Short Title:	Rethinking Guardianship.	(Public)
Sponsors:	Representatives Farmer-Butterfield, Hardister, White, and R. Turner (Primary Sponsors). *For a complete list of sponsors, refer to the North Carolina General Assembly web site.*	
Referred to:	Homelessness, Foster Care, and Dependency, if favorable, Health, if favorable, Rules, Calendar, and Operations of the House	

April 8, 2019

A BILL TO BE ENTITLED

AN ACT TO ESTABLISH A RETHINKING GUARDIANSHIP WORKGROUP TO STUDY AND RECOMMEND CHANGES TO CHAPTER 35A OF THE GENERAL STATUTES.

The General Assembly of North Carolina enacts:

SECTION 1.(a) The "Rethinking Guardianship Workgroup" is established. The Department of Health and Human Services shall convene the Workgroup to study the laws governing guardianship in this State, including proposed legislative changes and reforms to Chapter 35A of the General Statutes. The Workgroup shall be comprised of 24 members who shall be appointed as follows:

(1) Four members of the North Carolina House of Representatives, appointed by the Speaker of the House of Representatives.

(2) Four members of the North Carolina Senate, appointed by the President Pro Tempore of the Senate.

(3) Two members of the North Carolina Conference of Clerks of Superior Court, appointed by the President of the North Carolina Conference of Clerks of Superior Court.

(4) An employee of the North Carolina Administrative Office of the Courts, appointed by the Director of the Administrative Office of the Courts.

(5) The Secretary of the Department of Health and Human Services shall appoint the following members:

a. Two employees of the North Carolina Division of Aging and Adult Services of the Department of Health and Human Services.

b. An employee of the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services of the Department of Health and Human Services.

c. A faculty member of the University of North Carolina School of Government.

d. A member of the North Carolina Guardianship Association.

e. A member of Disability Rights North Carolina.

f. A member of the North Carolina Council on Developmental Disabilities.

g. A member of the North Carolina American Association of Retired Persons.

h. An individual who is a certified and active Guardian ad Litem.
i. An employee of a corporate guardianship organization located in this State.
j. An employee of a county department of social services in this State.
k. An individual with a disability or who has been under a guardianship in this State.
l. A faculty member of the University of North Carolina School of Social Work.

SECTION 1.(b) The Secretary of Health and Human Services shall designate one member as chair, and the Secretary shall convene the first meeting of the Workgroup. Each subsequent meeting shall be convened by the call of the chair. A quorum of the Workgroup shall be a majority of members.

SECTION 2. The Workgroup shall study all of the following:

(1) A mandate to consider alternatives to guardianships.
(2) A strategy to improve the quality, consistency, and availability of Multi-Disciplinary Evaluations (MDEs).
(3) A reformation and simplification of requirements for spousal guardianships.
(4) The review process and schedule for ongoing guardianships.
(5) The presumption of permanence after guardianship is implemented.
(6) The use of limited guardianships and restorations.
(7) The rights for those under a temporary, permanent, or limited guardianship.
(8) The addition of an appointed legal counsel in addition to a Guardian ad Litem.
(9) The terminology used and involved in guardianship.

SECTION 3.(a) Vacancies. – Vacancies occurring after the establishment of the Workgroup and before January 1, 2020, shall be filled by the original officer who made the appointment. Appointments to replace vacancies shall be made within 30 days of the date the vacancy occurred. If the member of the Workgroup holds an elected position, the member's resignation, removal, or any other event causing that member to no longer hold the elected position shall terminate the elected official's position on this Workgroup.

SECTION 3.(b) Compensation. – Members of the Workgroup shall receive subsistence and travel allowances at the rates set forth in G.S. 120-3.1, 138-5, or 138-6, as appropriate.

SECTION 3.(c) Administration. – The Department of Health and Human Services shall provide administrative support and shall assign clerical staff to assist the Workgroup. The North Carolina School of Government shall assign professional staff to assist the Workgroup.

SECTION 4. Report. – The Workgroup shall provide findings and recommendations, including any legislative proposals, to the Joint Legislative Oversight Committee on Health and Human Services by January 1, 2020, on all identified items in this act.

SECTION 5. The Workgroup shall terminate on January 1, 2020, or upon submitting its report to the Joint Legislative Oversight Committee on Health and Human Services, whichever occurs first.

SECTION 6. This act is effective when it becomes law.

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May 1, 2019

How the ADA Came to Be

Contents

- PowerPoint Presentation Handout

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How the ADA Came to Be

Disability Advocacy Conference – May 1, 2019

Larkin Taylor-Parker

Disability History in the U.S.

Early and 19th C. America

- Foster arrangements, abandonment
- Stigma, exclusion, institutionalization
- Disabled veterans with service-related disabilities often treated better than others with disabilities
- Disability experience different across race, class, gender, region…
- Ugly Laws

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Separate Settings

- Disability-specific institutions became larger and more prevalent in the 19th. c.
- People with I/DD, mental health disabilities, or seizure disorders particularly vulnerable to institutionalization
- Tragic lack of creativity about better ways to support people

Bunker brothers, famous North Carolinians with disabilities

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Eugenics

- The intentional breeding of human beings
- Eugenics proponents:
  - Supported childbearing by middle- and upper-class, straight couples of northwestern European ancestry who had no disabilities, had no criminal history, and were not Jewish
  - Opposed childbearing by everyone else
- National movement resulted in many forced sterilizations, particularly in NC

Victims of NC's Sterilization Program Protesting in 1971

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Veterans

- Rehabilitation started with combat veterans
- Some attempts during and after the Civil War
- Much more effort starting after WWI and continuing after WWII
- Goals of inclusion, employment, and independence

Wounded Soldiers in a Post-WWI Rehabilitation Program

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Polio

- Outbreaks frequent in the U.S. until the development of a vaccine in the 1950s
- Some people who contract the disease left with varying degrees of paralysis
- Cause of disability in FDR, Ed Roberts
- Drove innovation in rehabilitation in the civilian world
- Iron lung invented in 1929

Iron lungs

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GI Bill

- Post-WWII
- College funding for many veterans, although veterans of color were not fully included
- Veterans who had acquired physical disabilities from service went to college in large numbers
- Their needs increased campus accessibility

NC State struggled to house influx of WWII veterans

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1960s

- More effective treatment of mental health disabilities
- The Arc
- Social movements
- First published accessibility standards
- Independent living movement
- Ed Roberts

Don Galloway (L) and Ed Roberts (R), early ICL leaders

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Rolling Quads

- Other students with physical disabilities followed Roberts to Berkeley
- They lived together, fully enjoyed 1960s campus life
- They thought about and built what they needed for independent lives
- CILs

Three of the Rolling Quads

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1970s

- Growing activism
- Repeal of last Ugly Laws
- Exposes on institutions, deinstitutionalization
- Rehabilitation Act Passed 1973, though not enforced until later
- IDEA passed under its previous name

Activists block an inaccessible bus to demand passage of the Rehabilitation Act

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HEW Office Occupation - 1977

- Disability rights activists frustrated about lack of Rehabilitation Act regulations, occupied federal buildings across the country
- Occupation short in most places, but San Francisco protest led by Judy Heumann lasted 25 days
- Regulations finally promulgated, Section 504 enforced

A group of protesters at the 504 Sit-In

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Public Transportation

- Protests for accessible public transportation started in Denver in 1978
- This inspired interest in the issue and protest in other places
- ADAPT founded in 1983 to protest inaccessible public transit
- Air Carrier Access Act passed 1986, though problems persist, especially for wheelchair users

ADAPT protesters blocking an inaccessible bus in Denver

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1980s Activism

- Deaf President Now
- Fair Housing Amendments Act of 1988 prohibited discrimination in most housing
- Strong, well-connected coalitions of d/Deaf activists and activists with disabilities at this point
- Defense of 504 Regulations
- Still no comprehensive civil rights law covering totally private settings

Deaf President Now protest

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Effort to Pass the ADA

- 1980s activism:
  - Made connections and provided learning opportunities within the movement
  - Attracted media attention
  - Won over some politicians and members of the public to the cause of disability rights

ADA signed into law

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After ADA Passage

- Olmstead
- 2008 Amendments
- IDEA, Rehabilitation Act, and ADA's impact on society

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Impact

- Ongoing blowback
- Inclusion becoming more typical and expected
- More achievement by people with disabilities
- People who have no memory of the world before ADA are different

ADA 25 logo

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Effort to Pass the ADA

Getting the most comprehensive, ambitious civil rights statute for people with disabilities in the world passed was a long-term effort by thousands of people.

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Resources

- *A Disability History of the United States* – Kim Nielsen
- *Stuff You Missed in History Class*, Ed Roberts and Deaf President Now episodes
- Disability History Museum (virtual): https://www.disabilitymuseum.org/dhm/index.html
- Smithsonian's Disability Rights Movement Exhibit (virtual): https://www.si.edu/exhibitions/the-disability-rights-movement-2652

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May 1, 2019

Medicaid Transformation Listening Session

Contents

- PowerPoint Presentation Handout

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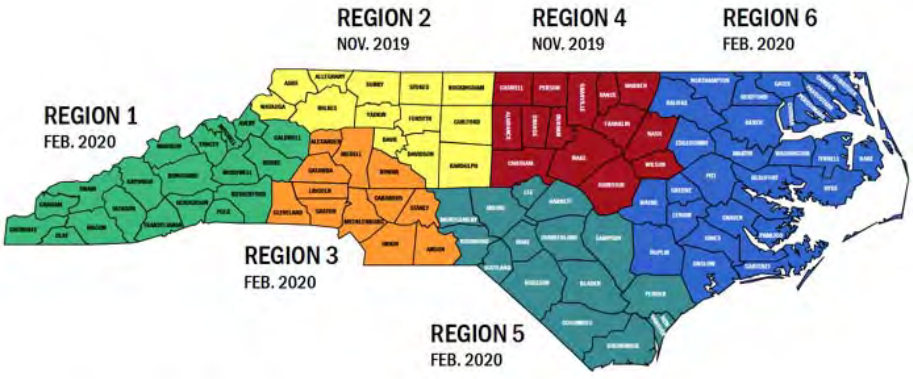
Medicaid Transformation Listening Session

Disability Advocacy Conference – May 1, 2019

Corye Dunn & Meisha Evans

Medicaid Managed Care Regions & Rollout Dates



Rollout Phase 1: Nov. 2019 – Regions 2 and 4
Rollout Phase 2: Feb. 2020 – Regions 1, 3, 5 and 6

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Standard Plan Populations

- Aged
- Blind
- Disabled
- NC Health Choice
- Aid to Families with Dependent Children
- Other Children
- Pregnant Women
- Infants and Children
- Breast and Cervical Cancer
- Legal Aliens

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Excluded Populations

- Medically Needy (excluding Innovations and Traumatic Brain Injury waiver participants)
- Health Insurance Premium Program
- Community Alternatives Program for Disabled Adults (CAP/DA)
- Community Alternatives Program for Children (CAP/C)
- Family Planning
- PACE
- Individuals partially dually eligible for Medicaid and Medicare
- Inmates
- Aliens
- Refugees

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Delayed Populations

- Foster Children
- Individuals with Significant Behavioral Health Disorders and Intellectual or Developmental Disabilities
- Long-Stay Nursing Home Residents
- Individuals eligible for both Medicaid and Medicare

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Enrollment for LME-MCO Populations After Standard Plan Launch

Tailored Plan Eligible – Innovations and TBI Waivers Includes Foster Children enrolled in the waivers	Remain with LME-MCO
Foster Children Not those enrolled in Innovations or TBI waivers	Remain with LME-MCO
Standard Plan Beneficiaries eligible for the Standard Plan AND Beneficiaries who don't meet Tailored Plan criteria	Phase-out of LME-MCOs
Tailored Plan Eligible – Non-Waiver Excludes Foster Children	Remain with LME-MCO with option to enroll in Standard Plan
Other populations excluded or delayed from managed care that meet Tailored Plan criteria Excludes Foster Children	Remain with LME-MCO
Other populations excluded or delayed from managed care that do not meet Tailored Plan criteria Excludes Foster Children	Remain with LME-MCO

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BH, TBI and I/DD Services Covered by Standard Plans and Tailored Plans

- Inpatient behavioral health services
- Outpatient behavioral health emergency room services
- Outpatient behavioral health services provided by direct- enrolled providers
- EPSDT
- Peer supports (DHHS will submit a State Plan Amendment)
- Partial hospitalization
- Mobile crisis management
- Facility-based crisis services for children and adolescents
- Professional treatment services in facility-based crisis program
- Outpatient opioid treatment
- Ambulatory detoxification
- Substance abuse comprehensive outpatient treatment program (SACOT)
- Substance abuse intensive outpatient program (SAIOP) pending legislative change
- Clinically managed residential withdrawal (DHHS will submit a State Plan Amendment)
- Research-based intensive behavioral health treatment
- Diagnostic assessment
- Non-hospital medical detoxification
- Medically supervised or ADATC detoxification crisis stabilization

*Underlined items are enhanced behavioral health services

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BH, TBI and I/DD Services Covered Exclusively by Tailored Plans

- Residential treatment facility services for children and adolescents
- Intermediate care facilities for individuals with intellectual disabilities (ICF/IID)
- Child and adolescent day treatment services
- Intensive in-home services
- Multi-systemic therapy services
- Psychiatric residential treatment facilities
- Assertive community treatment
- Community support team
- Psychosocial rehabilitation
- Substance abuse non-medical community residential treatment
- Substance abuse medically monitored residential treatment
- Clinically managed low-intensity residential treatment services (DHHS will submit a State Plan Amendment)
- Clinically managed population-specific high-intensity residential programs (DHHS will submit a State Plan Amendment)
- Innovations waiver services
- TBI waiver services
- 1915(b)(3) services (excluding Peer Supports if moved to State Plan)
- State-Funded BH and I/DD Services
- State-Funded TBI Services

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Disability Advocacy Conference
May 1, 2019

Medicaid Waivers: Emerging Issues & Appeal Strategies - Part 1

Contents

- PowerPoint Presentation Handout

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Medicaid Waivers Emerging Issues & Appeal Strategies – Part 1

Home and Community-Based Services (HCBS)

Lisa Nesbitt and Emma Kinyanjui
May 1, 2019

Medicaid Waivers

- Medicaid Waivers are intended to **keep people out of institutions** and provide long term services not otherwise available under Medicaid.
- Waivers are Home and Community-Based Service programs authorized by 42 U.S.C.S. § 1396n.
- Their purpose is to assist Medicaid beneficiaries to live in the community and avoid institutionalization, deviating from Medicaid's traditional "institutional bias."

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Medicaid Waivers

- States have some discretion in how they operate their waiver programs; however, programs must comply with the Americans with Disability Act's integration mandate:
  - States shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R § 35.130(d) (1998)
- The most integrated setting is one that "enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." 28 C.F.R. pt. 35, App. B (preamble to the regulations)

Three NC HCBS Waivers

North Carolina operates four Waivers that provide services to a limited number of persons in specific groups in the state:

- **CAP/C** Waiver for medically fragile children (overseen by DMA)
- **CAP/DA** Waiver for disabled adults (overseen by DMA)
- **Innovations Waiver** for individuals with intellectual or developmental disabilities (overseen by LME/MCO)
- **Traumatic Brain Injury** Waiver (3 year pilot)

DISABILITY RIGHTS NORTH CAROLINA

Background

- The 1915 (b)(c) Medicaid Waiver refers to 2 sections of the Social Security Act that allow states to apply for "waivers" from federal Medicaid policy.
- The (b) Waiver allows NC to use a Managed Care system and limit provider networks.
- The (c) Waiver provides Home and Community Based Services to Medicaid beneficiaries who would otherwise be institutionalized (also called the HCBS Waiver or Medicaid C). 42 U.S.C. § 1396n (c).

DISABILITY RIGHTS NORTH CAROLINA

Background

The (b)(c) Waiver operates as a "capitated" system.

- The LME/MCOs receive a set amount of money from the State each year from which to provide services to all Medicaid–eligible individuals in their catchment area. 42 C.F.R. § 438.6
- If MCO/LMEs spend less than allotted, savings are supposed to be used for additional services (sometimes called (b)(3) services).

DISABILITY RIGHTS NORTH CAROLINA

Background

- The idea of Waivers was to control escalating Medicaid costs.
- States have the discretion to choose the number of recipients that will be served in an HCBS Waiver program.
- Because NC limits the number of Waiver "slots," **there are waitlists** for people who need these long-term care services.

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Puppies!

Why are Puppies so Darn Cute?

- Waivers operate on a first-come, first-served basis.

- Get on the Waitlist.

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Why Are They Called Waivers?

- NC is permitted to "waive" certain Medicaid requirements in the administration of the program.
- Some rules that apply to recipients in a regular Medicaid program do not apply to recipients in a *Waiver* program.
- Examples:
  - Usually the **income of a spouse or parent** must be considered in determining Medicaid eligibility for a person living with that spouse/parent. This requirement is "waived" under the Innovations Waiver so that only the recipient's income is considered.

DISABILITY RIGHTS NORTH CAROLINA

Why Are They Called Waivers?

- Examples:
  - Medicaid Act requires states to provide **comparable services** in amount, duration and scope to all Medicaid recipients. This requirement is "waived" to allow Waiver services to be offered only to individuals who receive a Waiver slot.
  - Medicaid services are to be provided on a **statewide basis**. Under the Innovations Waiver, this requirement is waived to limit NC Innovations Waiver participants to legal residents (for the purpose of Medicaid eligibility) of the LME/MCO regions.

DISABILITY RIGHTS NORTH CAROLINA

CAP/C

Community Alternatives Program for Medically Fragile/Complex Children

- Medicaid program that provides home care for medically complex/fragile children through age 20 who would otherwise require long-term hospital care or nursing facility care.
- Only the *child's* income is used in determining whether the child is Medicaid eligible.
- By providing Case Management and other supports, CAP/C helps children remain at home with their families.

DISABILITY RIGHTS NORTH CAROLINA

CAP/C

- Overseen by DMA/DHB (Division of Health Benefits). Local Case Management Entities provide the day-to-day operation of the waiver (and assist with entry into the program).
- Currently there are more slots than recipients so ***there is no waitlist*** (4,000 slots, 2,584 participants).
- Clinical Coverage Policy 3K-1 contains eligibility criteria and can be accessed at:
- https://files.nc.gov/ncdma/documents/files/3K-1_4.pdf

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CAP/C Eligibility

Who is Medically Fragile/Complex?

Eligibility for CAP/C requires that the recipient meet the Nursing Facility Level of Care and all of the following:

A. A primary medical diagnosis(es) (physical rather than psychological, behavioral, cognitive, or developmental) to include chronic diseases or conditions; and

B. A serious, ongoing illness or chronic condition requiring prolonged hospitalization (more than 10 days, or 3 admissions) within 12 months, ongoing medical treatments, nursing interventions, or any combination of these; and

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CAP/C Eligibility

Who is Medically Fragile/Complex?

C. A need for life-sustaining devices or life-sustaining care to compensate for the loss of bodily function, including but not limited to endotracheal tube, ventilator, suction machines, dialysis machine, Jejunostomy Tube and Gastrostomy Tube, oxygen therapy, cough assist device, and chest PT vest. (New language 3/2018)

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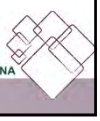

CAP/C Services

A. Assistive technology, Home accessibility and adaptation, and Vehicle Modifications combined budget of $28,000 per 5 year Waiver cycle
B. CAP/C in-home aide;
C. Care advisor;
D. Case management;
E. Community transition service;
F. Financial management services (for those who self-direct their services;

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CAP/C Services

H. Participant goods and services;
I. Pediatric nurse aide services;
J. Respite care (institutional and non-institutional);
K. Specialized medical equipment and supplies; and
L. Training, education and consultative services.

Services are defined in Appendix B to Clinical Coverage Policy 3K-1

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Applying for CAP/C

- Contact the Case Management Entity in your county: https://files.nc.gov/ncdma/CAPC_Contacts_By_County_2016_08_08.pdf
- Case Managers help coordinate a child's health care as well as social, educational, and other services related to the child's health care needs.
- They will submit a Service Request Form (SRF) and Physician Attestation to determine basic eligibility criteria for Level of Care and participation in the CAP/C Waiver.
- Authorization is for one year and must be renewed annually.

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What's New?

- Independent Assessment Entity (IAE)
- Entry into CAP/C will require assessment by an independent agency. Thereafter, the case management entity can certify that program criteria are met.
- Nutritional Supplements can be provided under Participant Goods and Services.

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CAP/C – Consumer Direction

- Allows a Medicaid beneficiary or representative to act in the role of **Employer of Record** to direct personal care services.
- Beneficiary can choose the employee to provide Personal Care Services.
- Set pay rate for employee.
- Design work schedule based on medical and functional needs.
- Not available to CAP/C beneficiaries approved for State Plan Nursing service.

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CAP/C and EPSDT

- **EPSDT** (Early and Periodic Screening, Diagnostic and Treatment) is the federal Medicaid benefit that says Medicaid must provide all **medically necessary** health care services to **Medicaid-eligible** children (children under 21). 42 U.S.C. § 1396d(r)(5).
- EPSDT services include any medical or remedial care that is **medically necessary** to **correct** or **ameliorate** a defect, physical or mental illness, or condition. **"Ameliorate"** means to improve **or** maintain the recipient's health in the best condition possible, compensate for a health problem, prevent it from worsening, or prevent the development of additional health problems.

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EPSDT Coverage and CAP Waivers

- ANY child enrolled in a CAP program can receive BOTH waiver services and EPSDT services.
- Waiver services are not a part of the EPSDT benefit.
- Any request for services for a CAP recipient under age 21 must be evaluated under BOTH the waiver and EPSDT.
- If enrolled in CAP/C, the cost of the recipient's care (including EPSDT services) must not exceed the waiver cost limit ($129,000). If enrolled in the Innovations Waiver, prior approval must be obtained to exceed the waiver cost limit.

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EPSDT Coverage and CAP Waivers

- **Caution:** NC requires that some services that appear to be available under CAP/C must be requested through EPSDT first/separately.
- Participant Goods and Services (new service with the new Waiver) and some medical supplies may be denied as a CAP/C request because the State requires a separate EPSDT request.
- Children on CAP/C also have access to regular Medicaid services, like physical therapy, occupational therapy, speech therapy, and medical equipment.
- All denials require that the state issue full appeal rights.

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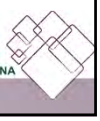

When a CAP/C Recipient Turns 21

- CAP/C recipients may receive an Innovations Waiver slot (or a CAP/DA slot) because there are “reserved” Waiver slots for individuals aging out of CAP/C that are “prioritized” for the CAP/C population.
- The CAP/C Case Manager begins the transition plan 12 months prior to the transfer at age 20.

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CAP/DA

Community Alternatives Program
for Disabled Adults

- CAP/DA allows elderly and disabled adults 18 and up to receive supports and services in their own home **or the home of a caregiver** as an alternative to nursing home placement.
- Must be at risk of being placed in a nursing facility or must be a current resident of a facility and wish to return to a private residence (beneficiary, relative’s home or caregiver’s home).

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CAP/DA

- Must be able to show that health, safety, and well-being can be maintained at home within the Medicaid cost limit.
- Provided where no household member, relative or caregiver is able or willing to meet the needs of the recipient.
- Eligibility criteria found in Clinical Coverage Policy 3K-2:

https://files.nc.gov/ncdma/documents/files/3K2_2.pdf

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CAP/DA Eligibility Requirements

- Must be 18 or older.
- Require nursing home level care.
- Be at risk of nursing home placement without community-based care.
- Meet strict financial eligibility criteria (must be low-income).
- CAP/DA eligibility is determined by the income and assets of the beneficiary only (**not** the spouse or other family members).

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CAP/DA Priority Slots

- Priority is given to:
  - Individuals who want to come out of an institution; and
  - Those in need of protection from abuse and neglect.
- In other words, individuals in these situations can jump ahead of the wait list.

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CAP/DA

CAP/DA provides extensive home and community-based services, which may include some services not covered by regular Medicaid, such as:

- Adult day programs
- More extensive home care (but not 24-hour care)
- Supplies such as incontinence products and nutritional supplements

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CAP/DA Background

- Program is overseen by DMA.
- Local Case Management Entities provide the day-to-day operation of the waiver.
- Case Managers coordinate services and monitor the care that is provided as needs change.
- The two options under the CAP/DA Program are:
  - CAP/DA, the traditional option; and
  - CAP/Choice, the consumer-directed option.

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CAP/Choice (Participant-Directed)

- Under CAP/Choice, participants can hire family members (or whomever they choose) to provide personal assistance services. **In other words, the adult children of aging parents can be paid to be their caregivers.**
- The participant/care recipient is the "employer." The care provider submits timesheets for the hours of care they provide to a third-party agency. The third party bills Medicaid, receives payment from Medicaid, withholds taxes, unemployment insurance and administrative fees and pays the care provider.

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CAP/DA Background

- Plans are authorized for 1 year.
- Must be re-authorized every 12 months through a Continuing Needs Review (CNR).
- Can be over the Medicaid income limit and still qualify for CAP/DA Medicaid. The Beneficiary will have a deductible based on income.

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CAP/DA – Getting Started

Is there a waitlist?

- Yes. It is much shorter than the Innovations Waiver waitlist. Waitlist depends on the county that recipient resides in.
- Entry into the program is by contact with the Local Lead Agency for your county. See the Lead Agency list at: https://www2.ncdhhs.gov/dma/cap/CAPDA_ContactList_050214.pdf
- Case Manager from Local Lead Agency submits Service Request Form (SRF) along with the Physician Attestation to determine eligibility.

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CAP/DA – Getting Started

- Beneficiary may be living in an institution (such as a nursing facility) at the time of application, screening, and assessment, but must be discharged to a primary private residence before they can receive in-home services.
- Beneficiaries residing in a nursing home for at least 3 continuous months who want to return to a community setting can be given higher priority on the Waitlist.

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CAP/DA Services

A. Adult day health
B. In-home aide personal care
C. Home accessibility and adaptation, and Assistive Technology - $13,000/life of Waiver (proposed)
D. Meal preparation and delivery
E. Institutional respite services
F. Non-institutional respite services
G. Personal Emergency Response Services
H. Specialized medical equipment and supplies

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CAP/DA Services

I. Participant goods and services ($800 annually)
J. Community Transition and Integration services ($2,500/ 5 yrs)
K. Training, education and consultative services
L. Assistive technology ($3,000/life of Waiver)
M. Case management
N. Care advisor (CAP/Choice only)
O. Personal assistant (CAP/Choice only)
P. Financial management services (CAP/Choice only)

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New Waiver; Significant Changes

- Independent Assessment Entity
- **Coordinated Caregiving:** Can have live-in Caregiver
- Non-Medical Transportation
- Combined limits for AT and home modifications
- Community Transition

DISABILITY RIGHTS NORTH CAROLINA

Innovations Waiver

- Home and Community Based Service program providing support for individuals with **intellectual and/or developmental disabilities**.
- Must be at risk of institutionalization in an Intermediate Care Facility for Individuals with Intellectual Disabilities (**Clinical Coverage Policy 8E**).
- Goal is to promote choice, control, and community integration as an alternative to institutionalization.
- **NOTE**: Eligibility determined based on income of *beneficiary*, not the family.

DISABILITY RIGHTS NORTH CAROLINA

Innovations Waiver

- Covered in **Clinical Coverage Policy 8P**.
- Limited number of "slots" available.
- Services provided on a first-come, first-served basis.
- Waitlist (also called Registry of Unmet Needs) can be 10 years or more.
- Administered by LME/MCOs, though DMA/DHB still responsible for oversight.
- Priority status given on the the waitlist in limited circumstances.

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Innovations Waiver Eligibility Criteria

1. Must **require active treatment** in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID). The following are characteristics commonly associated with the need for active treatment (**Clinical Coverage Policy 8E**):
   - Inability to take care of most personal needs
   - Inability to understand simple commands
   - Inability to communicate basic needs and wants
   - Inability to be employed at a productive wage level without systematic long-term supervision or support
   - Inability to learn new skills without aggressive and consistent training

DISABILITY RIGHTS NORTH CAROLINA

Innovations Waiver Eligibility Criteria

2. Beneficiary must have a diagnosis of an intellectual and/or developmental disability or a condition that results in impairment of general intellectual functioning or **adaptive behavior similar to that of persons with intellectual disabilities**. Autism Spectrum Disorder and Cerebral Palsy are examples of conditions that might negatively impact adaptive behavior or functioning, *regardless of the individual's IQ or cognitive ability*.

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Innovations Waiver Eligibility Criteria

3. The condition must have manifested before the individual turned age 22.
4. The condition will likely continue indefinitely.
5. The condition must result in "substantial functional limitations" in **three or more of the following six major life activities:** self-care, receptive and expressive language, learning, mobility, self-direction, and capacity for independent living. (**Clinical Coverage Policy 8E**)

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Innovations Waiver Eligibility Criteria

Substantial Functional Limitation

- "Substantial functional limitation" is not clearly defined. However, DMA Clinical Coverage Policy 8E lists the six areas of major life activity that are considered in determining whether an individual qualifies for Waiver services and explains what a "substantial functional limitation" is for each of the categories.
- See Attachment B to Clinical Coverage Policy 8E.
- https://files.nc.gov/ncdma/documents/files/8E_0.pdf

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Innovations Waiver: Getting Started

- Contact the LME/MCO for your county and request to be placed on the Waitlist. There are currently 7 LME/MCOs. https://www.ncdhhs.gov/providers/lme-mco-directory
- Refusal to place a beneficiary on the waitlist is appealable.

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Innovations Waiver: Getting Started

- The LME/MCO should begin the screening process, which will include a psychological evaluation that contains both intellectual testing as well as an adaptive behavioral assessment.
- Having an IQ that is "too high" is **NOT** an acceptable reason to deny placing a beneficiary on the waitlist.
- A decision not to place a beneficiary on the waitlist can be appealed by filing a contested case petition with the Office of Administrative Hearings.

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Innovations Waiver: Getting Started

- All Waiver participants must have their support needs evaluated through the Supports Intensity Scale (SIS). The SIS is designed to evaluate general, medical, and behavioral needs, and is administered when an individual enters the Waiver program.
- SIS re-assessments occur every two years for participants between the ages of 5 and 15, and at least every 3 years for participants 16 years of age and older. MCOs use the SIS score in their determination of the amount of services that will be approved; it is crucial that the SIS accurately reflect the enrollee's needs.

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Innovations Waiver Services

Base Budget Services are core habilitation and support services:

- Community Networking Services
- Day Supports
- Community Living and Support (includes services previously called In-Home Skill Building, In-Home Intensive, and Personal Care)
- Respite
- Supported Employment

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Innovations Waiver Services

Non-Base Budget Services are preventative services and equipment (also called Add-Ons):

- Residential Supports (services that enable someone to live in a group home or Alternative Family Living setting)
- Supported Living (a service that allows someone to remain in their home with daily service or the help of a live-in caregiver)
- Assistive Technology Equipment and Supplies
- Home Modifications
- Vehicle Modifications

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Innovations Waiver Services

- Community Navigator
- Community Transition Services
- Crisis Services
- Financial Support Services
- Individual Goods and Services
- Natural Supports Education
- Specialized Consultation Services

Cost Limit for Innovations Waiver is $135,000/yr.

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Innovations Waiver Services

- The results of the SIS and the "level" assigned (A-G), is a **guideline** that does not constitute a binding limit on the amount of services you can request or receive.

- Recipients should request the services they need, even if the cost is more than the "budget guideline" prepared by the LME/MCO.

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Innovations Waiver RaDSE

Relative as Provider (parent providers)

- Applies to waiver participants ages 18 and older who live with a relative or legal guardian who is employed by a waiver provider agency.
- Relatives are defined as those related by blood or marriage. However, spouses cannot be providers.
- **Community Living and Supports is the only waiver service that a RaDSE may provide**.
- Attachment G to Clinical Coverage Policy 8P (Relative as Provider).

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Innovations Waiver RaDSE

- Parents may provide 40 hours/wk of services without approval from the LME/MCO.
- Any more than 40 hours requires approval from the LME/MCO.
- Justification needs to be provided as to why there is no other qualified provider to provide CLS if more than 40/wk hours are to be provided
- Currently, there is a 56 hours per week limit set for those not grandfathered in as of 12/31/2015.

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"Natural Supports" & Service Cuts/Denials

- MCOs have justified service cuts by suggesting that "natural supports" should "fill in" for cuts in service hours.
- Natural supports are defined as unpaid supports that are provided ***voluntarily*** to the individual in lieu of waiver services and supports.
- An amendment to the managed care regulations in 2014 added the requirement that **natural supports are voluntary and may not be compelled**. (79 Fed. Reg 2948, 3008 (Jan. 16, 2014); 42 C.F.R. § 441.301(c)(2)(v)).

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Innovations Waiver - What's New?

- **New** Waiver participants may **not** receive Community Living and Supports if they are living independently in their own home (rather than the home of their family).
  - The services available will be Supported Living or Supported Living Periodic.
- If you currently receive CLS in your own home, you will be grandfathered in and may continue to receive CLS.

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Traumatic Brain Injury (TBI) Waiver

- Approved by CMS and live since September 2018.
- A 3 year pilot program only available to individuals living in the Alliance Behavioral Healthcare (LME-MCO) catchment area (Wake, Durham, Johnston and Cumberland counties).
- Will serve approximately 107 individuals over the 3 years of the pilot program.
- Currently serving 5 individuals with 17 "in process."
- Get on the "interest" registry if you think you qualify.

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Traumatic Brain Injury (TBI) Waiver

- Must have received TBI at or after age 22.
- Must Meet the requirements for eligibility for Skilled Nursing Facilities (SNF) like nursing homes, and/or eligibility for Specialized Hospital Level of Care.
- Waiver cost limit is $135,000.
- Relatives/legal guardians may **not** furnish Waiver services.

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TBI Waiver Services

- Adult Day Health
- Day Supports
- Personal Care
- Residential Supports
- Respite
- Supported Employment
- Extended State Plan service: OT, PT, SLP
- Assistive Technology
- Cognitive Rehabilitation (CR)

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TBI Waiver Services

- Community Networking
- Community Transition
- Crisis Supports Services
- Home Modifications
- In Home Intensive Support
- Life Skills Training
- Natural Supports Education
- Resource Facilitation
- Specialized Consultation
- Vehicle Modifications

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TBI Resource

- Brain Injury Association of North Carolina (BIANC) http://www.bianc.net/
- Alliance Behavioral Health: https://www.alliancehealthplan.org/consumers-families/traumatic-brain-injury-tbi/

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Waiver Waitlists

REMINDER

Get on the Waitlist

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Resources

- Innovations Waiver Application (approved by CMS)
  https://files.nc.gov/ncdma/documents/Medicaid/Innovations/1915c-home-community-based-services-waiver_application.pdf
- Innovations Waiver, Clinical Coverage Policy 8P
  https://files.nc.gov/ncdma/documents/files/8-P.pdf
- Innovations Waiver, Clinical Coverage Policy 8E
  https://files.nc.gov/ncdma/documents/files/8E_0.pdf

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Resources

- CAP/C Waiver
  https://files.nc.gov/ncdma/https___wms-mmdl.cdsvdc.pdf
- CAP/C, Clinical Coverage Policy 3K-1
  https://files.nc.gov/ncdma/documents/files/3K-1_4.pdf
- NC EPSDT Policy Instructions Update
  https://files.nc.gov/ncdma/documents/Medicaid/EPSDT/epsdtpolicyinstructions.pdf

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Resources

- CAP/DA, Clinical Coverage Policy 3K-2
  https://files.nc.gov/ncdma/documents/files/3K2_2.pdf
- TBI Draft Waiver
  https://files.nc.gov/ncdma/documents/files/TBI_Waiver_Draft-for_Public_Comment_2016_01.pdf
- NC DHHS TBI Information
  https://www.ncdhhs.gov/assistance/disability-services/traumatic-brain-injury

DISABILITY RIGHTS NORTH CAROLINA

Contact Information

Disability Rights North Carolina

3724 National Drive, Suite 100

Raleigh, NC 27612

919.856.2195

877.235.4210

888.268.5535 TTY

www.disabilityrightsnc.org

DISABILITY RIGHTS NORTH CAROLINA

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

Medicaid Waivers: Emerging Issues & Appeal Strategies - Part 2

Contents

- PowerPoint Presentation Handout

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Medicaid Waivers: Emerging Issues & Appeal Strategies - Part 2

May 1, 2019

Joshua Prater, Paralegal
Tadra Martin, Attorney

Key Terminology

- **Single State Agency**: NC Department of Health and Human Services (NC DHHS) is the administrative agency ultimately responsible for oversight of the state Medicaid plan and any Medicaid waiver programs.
- **LME/MCO:** The Local Management Entity/Managed Care Organization is responsible for authorizing behavioral health services (mental health, developmental disabilities, and substance abuse services) for individuals in their designated geographic catchment area.
- **Utilization Management (UM)**: An Internal LME/MCO division that makes the decision to approve, reduce, deny, suspend, or terminate services.

2

Key Terminology

- **Reconsideration:** The first step in the appeal process for services authorized through an LME/MCO that allows the LME/MCO to internally review the initial decision and either uphold the denial, reduction, or termination of services or reverse the decision.
- **State Fair Hearing:** The process for challenging a denial, reduction, or termination of Medicaid services. Also referred to as a "contested case hearing."
- **Office of Administrative Hearings (OAH):** An independent quasi-judicial agency that oversees the state fair hearing process.
- **Administrative Law Judge:** An impartial judge who presides over contested cases hearings at OAH.

3

Key Terminology

42 C.F.R. § 438.400 (July 1, 2017)

Adverse benefit determination means any of the following:

(1) The denial or limited authorization of a requested service, including determinations based on the type or level of service, requirements for medical necessity, appropriateness, setting, or effectiveness of a covered benefit.

(2) The reduction, suspension, or termination of a previously authorized service.

(3) The denial, in whole or in part, of payment for a service.

(4) The failure to provide services in a timely manner, as defined by the State.

Continued on the next slide

4

Key Terminology

42 C.F.R. § 438.400

5) The failure of an MCO, PIHP, or PAHP to act within the timeframes provided in § 438.408(b)(1) and (2) regarding the standard resolution of grievances and appeals.

(6) For a resident of a rural area with only one MCO, the denial of an enrollee's request to exercise his or her right, under § 438.52(b)(2)(ii), to obtain services outside the network.

(7) The denial of an enrollee's request to dispute a financial liability, including cost sharing, copayments, premiums, deductibles, coinsurance, and other enrollee financial liabilities.

5

Key Terminology

- **1915(b) Waiver**: Derived from Section 1915(b) of the Social Security Act and allows the State to offer Medicaid services with "managed care" features.

- **1915(c) Waiver**: Derived from Section 1915(c) of the Social Security Act and allows the State to offer community-based services not otherwise available under Medicaid to a specific population (Innovations, CAP/DA, & CAP/C).

6

Key Terminology

- **NC Innovations Waiver**: A home and community-based service waiver that provides services and supports for people with intellectual and/or developmental disabilities that are at risk for institutionalization in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IDD).
- **CAP/DA Waiver**: A home- and community-based service waiver that provides in-home services to the elderly and disabled adults ages 18 and up as an alternative to nursing home placement.
- **CAP/C Waiver**: A home- and community-based service waiver that provides services to children at risk for institutionalization in a nursing home. It is available to any child from birth through 20 years of age who meet both the Medicaid eligibility and the CAP/C eligibility criteria. Newest iteration took effect March 1, 2018.

7

Accessing Services in North Carolina

NC Service Delivery System

- NC's service delivery system is siloed:
  - Physical Health services (Fee-for-Service)
  - Behavioral Health services (Managed Care)
- Individuals can receive physical health and behavioral health services through several different funding streams/programs:
  - State Funded Services (NC)
  - Medicaid State Plan (Federal matching funds program)
  - Medicaid Waivers (HCBS)

9

How Do I Access Services?

Physical Health Services:

- Contact a Medicaid-enrolled provider
- Fee-for-Service

Behavioral Health Services:

- Contact your LME/MCO to obtain prior approval
  - Mental Health Services
  - Substance Abuse Services
  - Intellectual/Developmental Disability Services
- Capitated Rate

10

What are LME/MCOs?

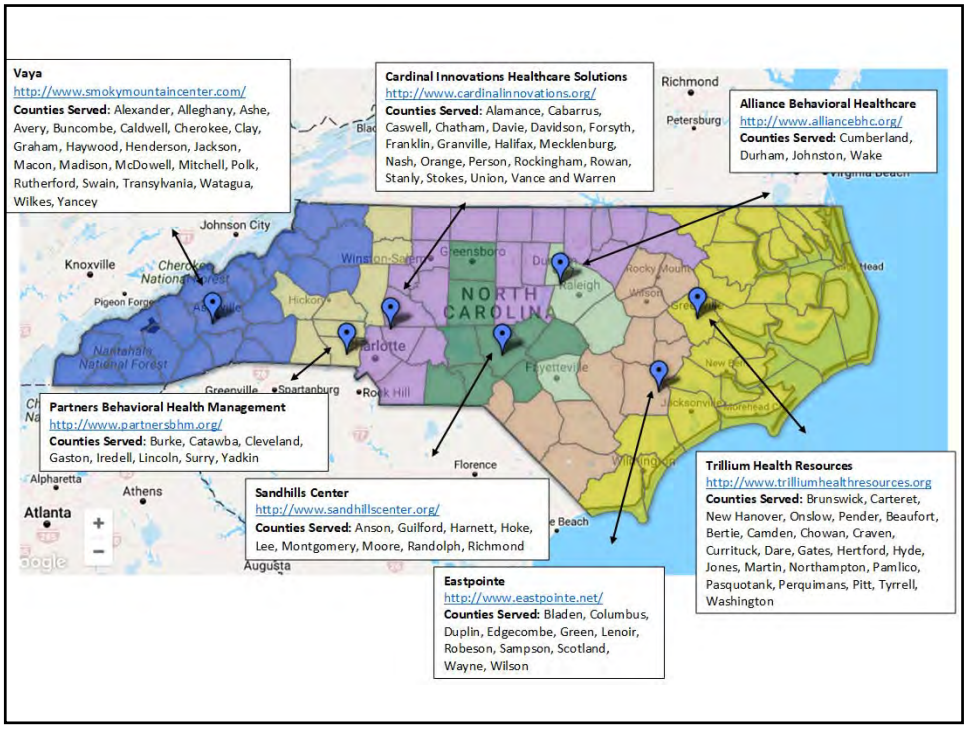
- Local Management Entity/Managed Care Organizations (LME/MCOs) are quasi-governmental entities that contract with the NC Department of Health and Human Services (NC DHHS), to provide management and oversight of the public system of **mental health, developmental disabilities, and substance abuse services at the community level.**
- LME/MCOs are publicly funded entities that are subject to both state law and federal managed care regulations.

11

What are LME/MCOs?

- LME/MCOs are accountable to NC DHHS/DMA, which retains oversight of the administration of the State's Medicaid program and is ultimately responsible for ensuring compliance with Medicaid rules and regulations.
- Currently, there are 7 LME/MCOs operating within NC: Alliance, Cardinal Innovations, Eastpointe, Partners, Sandhills, Vaya, and Trillium Health Resources.

12



What Services are Under the Managed Care System?

- Innovations Waiver Program (formerly CAP-MR/DD)
- State-Funded (IPRS) MH/DD/SA Services (e.g., Developmental Therapy)
- Medicaid Mental Health State Plan Services (e.g., Psychosocial Rehabilitation, Community Support Team, Assertive Community Treatment Team, Residential Services for Children)
- B3 services – available to Medicaid eligible persons on the waitlist. B3 services differ among the MCOs, so check with your MCO. B3 service denials are appealable.

14

What Services are Not Currently Under the Managed Care System?

- Community Alternatives Program for Children (CAP/C)
- Community Alternatives Program for Disabled Adults (CAP/DA, CAP Choice)
- Medical services offered under the Medicaid State Plan (e.g., Hospital, Nursing Home, Private Duty Nursing, PT, OT, ST, Dental, Durable Medical Equipment)
- Medicaid State Plan Personal Care Services

15

What is Due Process?

- Medicaid enrollees have a property interest in Medicaid benefits and are entitled to receive medically necessary services through the state's Medicaid program. Therefore, enrollees' benefits are protected by the Due Process Clause of the U.S. Constitution.
- "Due process" refers to constitutional and statutory requirements for the State to provide Medicaid enrollees with **written notice and an impartial hearing** before it (or its contractors) denies, reduces, suspends, or terminates Medicaid-covered services.
  - Adequate notice includes: the specific regulations supporting the action, an explanation of the reasons for the proposed action, and information on how to appeal.

16

What are My Rights Related to Requesting Services from a LME/MCO?

- Eligible individuals have the right to request and receive medically necessary services in an Individualized Service Plan (ISP) from the array in the Waiver program.
- Enrollees have the right to request the types of services, in the amount and duration needed, for up to the entire year of their annual ISP.
- LME/MCO Care Coordinators should assist enrollees in making requests for services in a manner consistent with the desires of the enrollee.

17

What are My Rights Related to Requesting Services from a LME/MCO?

- Enrollees have the right to make new requests for services at any time, ***including during an appeal***.
- Enrollees/guardians cannot be forced or pressured to sign a plan that is incomplete or does not contain all services the enrollee wants to request.
  - Do not refuse to sign a plan, instead, insist on signing a plan that has all of the services that you need.
- Care Coordinators cannot state that all services will stop if the enrollee does not submit a request within an assigned budget.

18

What are My Rights Related to Requesting Services from a LME/MCO?

- LME/MCOs cannot refuse to receive or process a request for services while an appeal is pending.
- LME/MCOs must issue a written notice of decision regarding its determination to either authorize, deny, or reduce services once a request has been made within 14 days.
- LME/MCOs cannot attempt to influence, limit, or interfere with an enrollee's (or provider acting on behalf of an enrollee) decision to file a grievance or an appeal.

19

Appealing the Reduction, Denial, Suspension, or Termination of Services

20

What Can Be Appealed?

- Medicaid Service under State Plan (OAH)
- LME/MCO Behavioral Health Services, including Innovations Waiver and B3 Services (OAH)
- State (IPRS)-funded services (DHHS only, no fair hearing)
- Only State "actions/adverse determinations" regarding federal entitlements triggers Due Process protections. An ***"action"*** occurs when the State or its contractor ***makes a decision (or adverse determination) to reduce, suspend, deny, or terminate a request for Medicaid-funded services***, including partial approvals or when a service is authorized for less than the requested time period.

21

How Do I Appeal a Denial of Services?

It depends on the service. There are <u>different</u> steps in the appeals process for each type of service based on the funding source.

Medicaid State Plan Service, Non-Innovations Waiver
- E.g., Private Duty Nursing, PT, OT, ST, DME, PCS, CAP/C, CAP/DA
- Mediation→OAH Hearing
- Need to show medical necessity

LME/MCO Medicaid Service, Innovations Waiver, B3 Services
- E.g., ACTT, PRTF, Community Living & Supports, Day Supports
- Internal LME/MCO Reconsideration→Mediation→OAH Hearing
- Need to show medical necessity

State-Funded/IPRS (10A NCAC 27G .7004)
- E.g., Developmental Therapy, Respite
- MCO review→If the reason is lack of money, the MCO wins
- Appeal to DHHS, but no robust due process rights through the state fair hearing process

22

APPEALING A MEDICAID (NON-INNOVATIONS WAIVER) SERVICE

What Can Be Appealed?

NC Gen. Stat. § 108A-70.9A(a)-(b)

Adverse Determinations: A recipient of Medicaid services has the right to appeal when there has been a: denial, termination, suspension, or reduction of services.

The recipient learns of adverse determination (denial or reduction) through a written Notice of Decision.

Fill out & return the **"Hearing Request"** form to ALL the addresses on the form. Keep proof that appeal form was mailed or faxed.

You have 30 days from the date on the Notice to file the appeal form or you will lose your right to appeal. However, if you file **within 10 days** of the date on the notice, services should be **maintained with no interruption.**

If the appeal is filed within 30 days, but after the first 10 days, there may be a brief interruption of services. However, they will be reinstated.

24

What Can Be Appealed?

N.C.G.S. § 108A-70.9A(c)

- The Notice of Decision must be mailed at least 10 days before services will end or change and explain why the service was denied, terminated, suspended, or reduced.
- The Medicaid recipient has a right to examine his/her file and any documents used by DHHS in making its determination before and during hearing.
- Medicaid recipients also have the right to obtain an independent medical assessment at the agency's expense if the assessment could resolve the dispute.
- **Caution: DHHS does not have to notify a recipient's parent, guardian or legal representative unless there has been a written request to receive notice.**

25

APPEALING AN LME/MCO DECISION

What Can Be Appealed?

- Only LME/MCO "adverse determinations" can be appealed through the reconsideration/state fair hearing appeals process. All other complaints or issues would be considered a "grievance."
- When an "adverse determination" occurs, due process is required. Due process requires notice and an opportunity to be heard, i.e., reconsideration and hearing.

27

I Received a Notice of Decision from a LME/MCO Denying Services. What Next?

1. **Look at the Date on the Notice of Decision**
   - You have 60 days, from that date to file your request for Reconsideration Review with the LME/MCO (form and instructions will be included with the Notice).
2. **Look for a "clinical rationale" for the decision within the Notice**
   - LME/MCOs are required to provide this information which should explain the **medical reason** as to why the LME/MCO did not approve the requested service.
   - All Notices will provide a brief explanation for the denial. However, you are often required to call the LME/MCO to get the full clinical rationale/explanation.
3. **Submit any additional information supporting your position to the LME/MCO**

28

What is Reconsideration?

- **Reconsideration** is a required step before moving on to the fair hearing at OAH for services authorized by LME/MCOs. It gives the LME/MCO a "second look" at the request for services and any documents submitted with it.
  - The individuals who denied the initial request for services cannot participate in Reconsideration Review.
  - Consumers, guardians, and providers may submit additional information for the Reconsideration reviewers to consider.
- The LME/MCO has up to 45 days from the date it receives the request to complete the reconsideration, but usually decides more quickly (within 30 days).

29

What is Expedited Reconsideration?

- An enrollee may request an **expedited appeal for Reconsideration** when the time limits for completing a standard appeal could seriously jeopardize the individual's life or health or ability to attain, maintain, or regain maximum function.
- ***For expedited appeal requests made by providers on behalf of enrollees, the LME/MCO shall presume an expedited appeal is necessary.***
- If the request is approved, the LME/MCO will resolve the appeal no later than 3 business days.

30

What Happens After Reconsideration?

- If the LME/MCO approves the request at Reconsideration, the appeal is resolved.
- If the LME/MCO upholds the denial, you now have the right to access the fair hearing process at OAH.

Steps:

1. Look at the date on the Reconsideration Review Notice of Decision.
2. You have 120 days from that date to file your State Fair Hearing Request form with OAH (form and instructions will be included with the Notice).

31

I Have Appealed to OAH. What Next?

- After filing with OAH **(for both Traditional Medicaid and for services authorized by LME/MCOs),** the NC Mediation Network will contact you about participating in mediation. This is another opportunity for you to resolve the issue prior to a hearing at OAH. DRNC encourages you to participate.
- **Mediation** is a voluntary, informal process in which both parties are guided through a telephone discussion by a neutral, third-party mediator to see if the parties can reach a settlement.

32

I Have Appealed to OAH. What Next?

- ***You are not required to mediate, but if you agree and fail to participate (absent "good cause"), your appeal will be dismissed.***
- Mediation is a non-binding process and any **information shared at mediation is confidential and cannot be used at the hearing** by either side.
- You may submit new documentation to support your case, such as a letter from a clinician, to the mediator or directly to DHHS and/or the LME/MCO.

33

How do I Prepare for Mediation?

Prepare for the mediation as if it were the hearing:

- Have a doctor's letter or affidavit specifying in detail what service is needed and why the service is medically necessary.
- Be ready to explain what would happen if enrollee does not get the service. (i.e. Will the individual regress in some way?)
- Understand the individual's needs and have a list of inaccuracies that you found in the Notice of Decision or the LME/MCO's clinical rationale.

34

How do I Prepare for Mediation?

- **Have a "number" ready.**
  - Could the enrollee accept fewer hours of the requested service without jeopardizing their health and safety? What number of hours can enrollee live with?
  - Could enrollee use another service instead of the one requested?
  - Failure to compromise at mediation means that you will proceed to OAH. **At OAH, you may receive all of the requested hours, or the original denial or reduction may also be upheld.**

35

How do I Prepare for Mediation?

- You have a right to see your entire file. You can request the file from your LME/MCO and/or DHHS.
- You are also required to provide any documentation that supports your case to both the LME/MCO (and/or DHHS) and OAH. If the documents are not submitted in a reasonable time, the LME/MCO or DHHS may ask for a continuance.
- New evidence is always allowed, even on the day of the hearing.

36

What Should I Expect Before the Hearing?

All hearings are conducted by video or telephone unless you request an In-Person Hearing.

Request for In-Person Hearing (in Raleigh at OAH): Individuals and/or their witnesses can always appear in Raleigh on the scheduled hearing date without making a special request to do so. ***If witnesses are unable to appear in person, they can always testify over the telephone.***

Request for In-Person Hearing (outside of Raleigh): If the individual's impairment limits travel, an in-person hearing may be held in another county closer to their residence. The ALJ will determine whether to grant the request and in what county the hearing will be held. ***If your request is granted, your witness will also be required to appear in person to testify.***

37

What Should I Expect Before the Hearing?

- OAH will provide written notice informing you of the date of the hearing and whether it will be by phone or in-person.
- If the enrollee fails to participate at the scheduled time, the appeal will be dismissed unless "good cause" is demonstrated within 3 business days.
- Documents that you want the judge to consider should be received by OAH (2 copies) and the LME/MCO (and/or DHHS) at least 5 business days prior to the hearing.

38

Can I File My Documents Electronically?

- OAH allows E-Filing for all parties involved in an appeal at no cost.
- Using the system, you can upload and file documents in any case to which you are a party, as well as view all documents and information in those case files for all cases filed after January 1, 2016.
- You can register for the e-filing system at: https://www.encoah.oah.state.nc.us/Login?ReturnUrl=%2fSecure%2fCase.aspx.
- If you have questions, you can contact the Clerk's office at 919-431-3000.

39

The OAH Hearing

What is the Applicable Statutory Authority?

N.C. General Statutes

- § 150B-22 *et seq.*
- Chapter 122C
- § 108 *et seq.*

Federal Statutes

- 42 U.S.C. § 1396 *et seq.* (Medicaid Act), and all corresponding regulations
- 42 U.S.C. § 12101 *et seq.* (Americans with Disabilities Act), and all corresponding regulations
- 29 U.S.C. § 794a (Rehabilitation Act), and all corresponding regulations

41

What is the Applicable Statutory Authority?

Rules, Regulation, Policy

- State Medicaid Plan
- Medicaid Clinical Coverage Policies
  (8P – Innovations, 3K-1 – CAP/C, and 3K-2 – CAP/DA)

Case Law

- ***Olmstead v. L.C.***, 527 U.S. 581 (1999), Supreme Court held that under ADA individuals with disabilities have the right to live in the community rather than in institutions.

42

What are the Issues for Hearing?

N.C.G.S. § 108D-15(l)

The hearing shall determine whether DHHS (or their contractor) substantially prejudiced the rights of the recipient/enrollee and if, based upon evidence at the hearing, DHHS or their contractor:

1. Exceeded its authority or jurisdiction;
2. Acted erroneously;
3. Failed to use proper procedure;
4. Acted arbitrarily or capriciously;
5. Failed to act as required by law or rule.

43

What Happens at the Hearing?

- The hearing will be in front of an Administrative Law Judge (ALJ).
- The enrollee has the burden of proof on all issues. N.C.G.S. § 108D-15(j).
- The hearing involves presenting evidence, including introducing documents, allowing someone to testify on your behalf (in-person or by telephone), and making arguments to the ALJ.
- ***The goal of the hearing is to prove that the requested amount of service is medically necessary, and that the decision to reduce, deny, or terminate was wrong.***

44

Who Are the Best Witnesses?

- **Clinicians** who can testify as to WHY the services are medically necessary.
  - OT, PT, Primary Care Physician, Psychologist, etc.
- **Direct Care Staff :** "CAP" Workers, Parent Providers, etc.
- The **recipient/enrollee**
- Anyone else with **first-hand knowledge of the functional limitations** of the enrollee who can speak to the benefits of the service and/or the harm to the enrollee if the requested service is not received including teachers, employers, family members, and friends.

45

How Do I Prove Medical Necessity?

- The evidence should demonstrate **why the Medicaid service is medically necessary** for the enrollee such as letters, medical/educational records, or photos.
- Letters of "medical necessity" or testimony from clinicians ***should take into account service definitions and the clinical coverage policy criteria.***
- Specifically, bring things that will help the ALJ understand:
  The type of service the enrollee needs;
  The level or amount of hours needed of the service;
  How the service has helped or will help;
  The consequences of not getting the service; and
  The service definition and/or a specific description of the type of service needed.

46

Why are Service Definitions Important?

- Service definitions describe the types of services that recipients/enrollees can obtain and the eligibility criteria to receive the service.
- LME/MCOs or DHHS rely on the criteria specified in the service definitions to determine if a request for services meets medical necessity and can be authorized.
- Clinicians need to be able to express why a particular service is medically necessary in the requested amount, frequency, and duration based on the criteria outlined in the definition.
- Service definitions for Medicaid covered services can be found in the NC Division of Medical Assistance's Clinical Coverage Policies. The various CCPs can be found at: https://ncdma.s3.amazonaws.com/s3fs-public/documents/files/ccp%20Index_0.pdf

47

Will I Receive Services During the Appeal?

Medicaid State Plan Services:

- If you file your State Fair Hearing Request Form to OAH within 10 days of the date on the Notice of Decision, services will continue pending appeal.
- If you file your State Fair Hearing Request Form to OAH after 10 days, but before 120 days, of the date on the Notice of Decision, you may have a break in services for a short period of time until your appeal is received by OAH, but then services will be reinstated.

48

Will I Receive Services During the Appeal?

Innovations Waiver and B3 Services:

- Enrollees will rarely receive contested services once the current authorization period expires, even though the appeal is still pending.
- Currently, LME/MCOs do not continue services pending an appeal **if the authorization period has expired** (relying on Federal Managed Care Regulations). This view is at odds with a Supreme Court ruling that entitles Medicaid recipients to a pre-termination hearing before a cut or termination goes into effect. *See Goldberg v. Kelly*, 397 U.S. 254 (1970).

Continued on next slide

49

Will I Receive Services During the Appeal?

- CMS approved a change to the Managed Care Regulations so that they are compatible with the Supreme Court ruling allowing enrollees to continue to receive services throughout the appeal process as long as:
  - The period covered by the original authorization has not expired, **and**
  - The enrollee timely files for continuation of benefits (that is, the enrollee requests continuation of benefits on or before 10 calendar days of the MCO sending the notice of adverse benefit determination).

50

Will I Receive Services During the Appeal?

State-Funded (IPRS Services):

- Because these services are funded with limited, discretionary state dollars, these services are not considered "entitlements" like other Medicaid services and may not continue pending an appeal.

51

Will I Receive Services During the Appeal?

Risk of recoupment by the LME/MCO

- While this is possible if the hearing is ultimately unsuccessful, DRNC is not aware that this has occurred with any frequency.

Documenting the Provision of Services during Appeal

- Parents/guardians and providers should continue to document any provision of services that you provide during an appeal, even if the services have not been authorized.
- LME/MCO contracts state: "[The LME/MCO] or the State must pay for disputed services, in accordance with State policy and regulations, if [the LME/MCO], or the State fair hearing officer reverses a decision to deny authorization of services, and the Enrollee received the disputed services while the appeal was pending."

52

When Will the ALJ make the Decision?

- Within 55 days of OAH's receipt of your request for an appeal, the ALJ will conduct the hearing and issue a ruling through a **Notice of Final Decision** that contains findings of fact and conclusions of law**.** NC Gen. Stat. § 108D-15(h)(1).
- The Notice of Final Decision will be sent directly to all parties. It will notify both parties of their right to seek judicial review of the decision in Superior Court.
  - The **petition for Judicial Review must be filed within 30 days** from the date on the written final agency decision.
  - **Proper Venue:** The petition must be filed in the Superior Court in the county where the person aggrieved by the administrative decision resides. If the person lives out of the state, then the petition must be filed in the county where the final decision was filed. NC Gen. Stat. § 150B-45. and 16 NCAC 03.127

53

Standard of Review by Superior Court

NC Gen. Stat. § 150B-51

Superior Court review of agency decisions are conducted by the court without a jury, and it is limited to affirming the decision, remanding the case to the agency for further proceedings, or reversing or modifying the agency's decision if the substantial rights of the petitioner may have been prejudiced because the agency's findings, inferences, conclusions, or decisions are:

1) In violation of constitutional provisions;
2) In excess of the statutory authority or jurisdiction of the agency;
3) Made upon unlawful procedure;
4) Affected by other error of law;
5) Unsupported by substantial evidence; OR
6) Arbitrary, capricious, or an abuse of discretion.

54

Standard for Attorney Fees

NC Gen. Stat. § 6-19.1

- The Superior Court (or OAH) may, in its discretion, allow the prevailing party (unless it's the State) to recover reasonable attorney's fees to be taxed as court costs against the agency if:
  - Agency acted without **substantial justification** in pressing its claim against the party; AND
  - There are **no special circumstances** that would make the award of attorney's fees unjust.
- **Burden is on State** to prove its position was substantially justified – *Walker v N.C. Coastal Resources Comm.*, 476 S.E. 2d 138 (1996).
- Party shall petition for the attorney's fees **within 30 days following final disposition** of the case. The petition shall be supported by an affidavit setting forth the basis for the request.

55

What if I Have a Complaint that is Not Related to a Denial of Services?

- Each LME/MCO must have a grievance process for complaints that are not related to a reduction in services. **This is an internal process.**
- A "grievance" is an expression of dissatisfaction about matters involving the LME/MCO, other than a service reduction, denial, suspension, or termination.
- The LME/MCO must respond to the grievance in writing within 90 days. There is no right to appeal the resolution of a grievance to OAH or any other forum.
- If you don't believe the care coordinator is acting in your best interest, you may request a new care coordinator.

56

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

Restrictive Interventions in Public Schools

Contents

- PowerPoint Presentation Handout
- N.C. General Statute § 115C-391.1
- NC DHHS Memo from Al Delia (November 13, 2012)
- Restraint and Seclusion: Resource Document (US Dept. of Education, May 2012)

DISABILITY RIGHTS NORTH CAROLINA

Restrictive Interventions in Public Schools

Disability Advocacy Conference – May 1, 2019

Virginia Fogg, Supervising Attorney
Andrea Martinez, Advocate
Kristine Sullivan, Supervising Attorney

Our work

- Direct representation
- Monitoring
- Investigations
- Policy

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The Law

- No federal law yet… ?
- N.C. General Statute § 115C-391.1

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What is Physical Restraint

- Physical force
- Restricts free movement of all or part of body

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Physical Restraint

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Physical Restraint: Permissible Use

- As reasonably needed to:
  - Obtain possession of weapon or dangerous object
  - Maintain order or prevent/break up fight
  - Defend self or others

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Physical Restraint: Permissible Use

- As reasonably needed to:
  - Prevent self-injurious behavior
  - Prevent imminent destruction to school or person's property
  - Escort safely

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Physical Restraint: Permissible Use

- As reasonably needed to:
  - Teach a skill
  - Calm or comfort
- As written in IEP, BIP or 504 Plan
- NOT solely for discipline

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What is Mechanical Restraint

- Device or material attached or adjacent to body
- Restricts free movement or normal access to any portion of body
- Student cannot easily remove

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Mechanical Restraint

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Mechanical Restraint: Permissible Use

- Properly used AT device
  - In IEP, BIP or 504 Plan, or
  - Prescribed by medical or related service provider

✓ View devices used with child or in classroom

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Mechanical Restraint: Permissible Use

- Seat belts or other safety restraints during transportation
- As reasonably needed to:
  - Obtain possession of weapon or dangerous object
  - Defend self or others

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What is Seclusion

- Confinement alone in enclosed space
- Prevented from leaving (e.g. locked door) or not capable of leaving (e.g. physical or intellectual ability)

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Seclusion

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Seclusion: Permissible Use

- As reasonably needed:
  - Obtain possession of weapon or dangerous object
  - Maintain order or prevent/break up fight
  - Behavior poses threat of imminent physical harm to self or others
  - Prevent imminent substantial destruction of school or person's property

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Seclusion: Permissible Use

- As written in IEP, BIP or 504 Plan
- NOT solely for discipline

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Seclusion: Requirements

- Monitored by adult in close proximity
- See and hear student at all times

✓View room

✓ Look in from outside

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Seclusion: Requirements

- Ends when behavior ends, or as in IEP/504
- Approved for use by LEA
- Appropriate lighting, ventilation, heating and cooling
- No objects that unreasonably expose to harm

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Seclusion: Requirements

- Lock
  - Physically held in place, or
  - Wired into fire alarm

✓ Examine lock

✓ Ask fire marshal to inspect

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A Word About Law Enforcement

- Law permits use of restraint and seclusion by law enforcement in lawful exercise of their duties

✓ Advocate with Sheriff's Office or Police Dept.

✓ School policies and contract

✓ Educate SRO

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Notice and Documentation

- Only certain incidents
  - Prohibited mechanical restraint
  - Physical restraint resulting in observable physical injury to student
  - Prohibited seclusion
  - Seclusion longer than 10 minutes or time allowed in IEP, BIP or 504 Plan

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Notice and Documentation

- Report must include:
  - Date, time, location and duration
  - Events leading to incident
  - Description of incident and interventions
  - Nature and extent of student injury

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Gaps, Best Practice & Advocacy

- Recourse limited
  - Litigation is challenging
  - US Dept. of Education Office for Civil Rights
  - NC Department of Public Instruction

✓ Focus on reducing and eliminating use

DISABILITY RIGHTS NORTH CAROLINA

Gaps, Best Practice & Advocacy

- Include in IEP, BIP or 504?
  - Limit type, duration or reason – but will not prevent use allowed by law
  - Require documentation and notice
  - May see as requirement or agreement

✓ Use to focus on positive interventions and prevention

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Gaps, Best Practice & Advocacy

- ✓ Use U.S. Dept. of Education document to advocate for best practices

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Gaps, Best Practice & Advocacy

- Principle 2: Never use mechanical restraint
- Principle 3: Only use when imminent danger of serious physical harm to self or others

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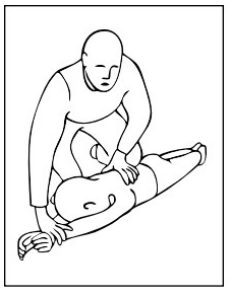
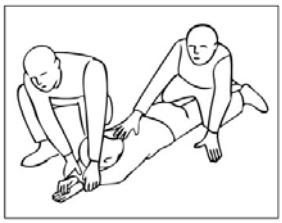
Gaps, Best Practice & Advocacy

- Principle 7: Never restrict breathing





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Gaps, Best Practice & Advocacy

- ✓ Advocate to ban prone restraint
  - NC DHHS ban
  - School practice
  - Exceptional Children Department procedure
  - Local Board of Education policy

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Gaps, Best Practice & Advocacy

- Principle 10: Only trained staff use
  - o Include training on collecting and analyzing data
- ✓ Attend training
- ✓ Collect data yourself
- ✓ Use DPI and OCR data

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Gaps, Best Practice & Advocacy

- Principle 13: Notify parent of every instance ASAP
- ✓ Request notice of all uses
- ✓ Collect data yourself
- ✓ Photograph and track injury

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3724 National Drive, Suite 100
Raleigh, NC 27612
Toll-Free: (877) 235-4210
Phone: (919) 856-2195

Website: www.disabilityrightsnc.org
Email: info@disabilityrightsnc.org

§ 115C-391.1. Permissible use of seclusion and restraint.

(a) It is the policy of the State of North Carolina to:

(1) Promote safety and prevent harm to all students, staff, and visitors in the public schools.

(2) Treat all public school students with dignity and respect in the delivery of discipline, use of physical restraints or seclusion, and use of reasonable force as permitted by law.

(3) Provide school staff with clear guidelines about what constitutes use of reasonable force permissible in North Carolina public schools.

(4) Improve student achievement, attendance, promotion, and graduation rates by employing positive behavioral interventions to address student behavior in a positive and safe manner.

(5) Promote retention of valuable teachers and other school personnel by providing appropriate training in prescribed procedures, which address student behavior in a positive and safe manner.

(b) The following definitions apply in this section:

(1) "Assistive technology device" means any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capacities of a child with a disability.

(2) "Aversive procedure" means a systematic physical or sensory intervention program for modifying the behavior of a student with a disability which causes or reasonably may be expected to cause one or more of the following:

a. Significant physical harm, such as tissue damage, physical illness, or death.

b. Serious, foreseeable long-term psychological impairment.

c. Obvious repulsion on the part of observers who cannot reconcile extreme procedures with acceptable, standard practice, for example: electric shock applied to the body; extremely loud auditory stimuli; forcible introduction of foul substances to the mouth, eyes, ears, nose, or skin; placement in a tub of cold water or shower; slapping, pinching, hitting, or pulling hair; blindfolding or other forms of visual blocking; unreasonable withholding of meals; eating one's own vomit; or denial of reasonable access to toileting facilities.

(3) "Behavioral intervention" means the implementation of strategies to address behavior that is dangerous, disruptive, or otherwise impedes the learning of a student or others.

(4) "IEP" means a student's Individualized Education Plan.

(5) "Isolation" means a behavior management technique in which a student is placed alone in an enclosed space from which the student is not prevented from leaving.

(6) "Law enforcement officer" means a sworn law enforcement officer with the power to arrest.

(7) "Mechanical restraint" means the use of any device or material attached or adjacent to a student's body that restricts freedom of movement or normal access to any portion of the student's body and that the student cannot easily remove.

(8) "Physical restraint" means the use of physical force to restrict the free movement of all or a portion of a student's body.

(9) "School personnel" means:

a. Employees of a local board of education.
b. Any person working on school grounds or at a school function under a contract or written agreement with the public school system to provide educational or related services to students.
c. Any person working on school grounds or at a school function for another agency providing educational or related services to students.

(10) "Seclusion" means the confinement of a student alone in an enclosed space from which the student is:
a. Physically prevented from leaving by locking hardware or other means.
b. Not capable of leaving due to physical or intellectual incapacity.

(11) "Time-out" means a behavior management technique in which a student is separated from other students for a limited period of time in a monitored setting.

(c) Physical Restraint:

(1) Physical restraint of students by school personnel shall be considered a reasonable use of force when used in the following circumstances:
a. As reasonably needed to obtain possession of a weapon or other dangerous objects on a person or within the control of a person.
b. As reasonably needed to maintain order or prevent or break up a fight.
c. As reasonably needed for self-defense.
d. As reasonably needed to ensure the safety of any student, school employee, volunteer, or other person present, to teach a skill, to calm or comfort a student, or to prevent self-injurious behavior.
e. As reasonably needed to escort a student safely from one area to another.
f. If used as provided for in a student's IEP or Section 504 plan or behavior intervention plan.
g. As reasonably needed to prevent imminent destruction to school or another person's property.

(2) Except as set forth in subdivision (1) of this subsection, physical restraint of students shall not be considered a reasonable use of force, and its use is prohibited.

(3) Physical restraint shall not be considered a reasonable use of force when used solely as a disciplinary consequence.

(4) Nothing in this subsection shall be construed to prevent the use of force by law enforcement officers in the lawful exercise of their law enforcement duties.

(d) Mechanical Restraint:

(1) Mechanical restraint of students by school personnel is permissible only in the following circumstances:
a. When properly used as an assistive technology device included in the student's IEP or Section 504 plan or behavior intervention plan or as otherwise prescribed for the student by a medical or related service provider.
b. When using seat belts or other safety restraints to secure students during transportation.

c. As reasonably needed to obtain possession of a weapon or other dangerous objects on a person or within the control of a person.
d. As reasonably needed for self-defense.
e. As reasonably needed to ensure the safety of any student, school employee, volunteer, or other person present.

(2) Except as set forth in subdivision (1) of this subsection, mechanical restraint, including the tying, taping, or strapping down of a student, shall not be considered a reasonable use of force, and its use is prohibited.

(3) Nothing in this subsection shall be construed to prevent the use of mechanical restraint devices such as handcuffs by law enforcement officers in the lawful exercise of their law enforcement duties.

(e) Seclusion:

(1) Seclusion of students by school personnel may be used in the following circumstances:
a. As reasonably needed to respond to a person in control of a weapon or other dangerous object.
b. As reasonably needed to maintain order or prevent or break up a fight.
c. As reasonably needed for self-defense.
d. As reasonably needed when a student's behavior poses a threat of imminent physical harm to self or others or imminent substantial destruction of school or another person's property.
e. When used as specified in the student's IEP, Section 504 plan, or behavior intervention plan; and
1. The student is monitored while in seclusion by an adult in close proximity who is able to see and hear the student at all times.
2. The student is released from seclusion upon cessation of the behaviors that led to the seclusion or as otherwise specified in the student's IEP or Section 504 plan.
3. The space in which the student is confined has been approved for such use by the local education agency.
4. The space is appropriately lighted.
5. The space is appropriately ventilated and heated or cooled.
6. The space is free of objects that unreasonably expose the student or others to harm.

(2) Except as set forth in subdivision (1) of this subsection, the use of seclusion is not considered reasonable force, and its use is not permitted.

(3) Seclusion shall not be considered a reasonable use of force when used solely as a disciplinary consequence.

(4) Nothing in this subsection shall be construed to prevent the use of seclusion by law enforcement officers in the lawful exercise of their law enforcement duties.

(f) Isolation. – Isolation is permitted as a behavior management technique provided that:

(1) The space used for isolation is appropriately lighted, ventilated, and heated or cooled.

(2) The duration of the isolation is reasonable in light of the purpose of the isolation.

(3) The student is reasonably monitored while in isolation.

(4) The isolation space is free of objects that unreasonably expose the student or others to harm.

(g) Time-Out. – Nothing in this section is intended to prohibit or regulate the use of time-out as defined in this section.

(h) Aversive Procedures. – The use of aversive procedures as defined in this section is prohibited in public schools.

(i) Nothing in this section modifies the rights of school personnel to use reasonable force as permitted under G.S. 115C-390.3 or modifies the rules and procedures governing discipline under G.S. 115C-390.1 through G.S. 115C-390.12.

(j) Notice, Reporting, and Documentation.

(1) Notice of procedures. – Each local board of education shall provide copies of this section and all local board policies developed to implement this section to school personnel and parents or guardians at the beginning of each school year.

(2) Notice of specified incidents:

a. School personnel shall promptly notify the principal or principal's designee of:

1. Any use of aversive procedures.
2. Any prohibited use of mechanical restraint.
3. Any use of physical restraint resulting in observable physical injury to a student.
4. Any prohibited use of seclusion or seclusion that exceeds 10 minutes or the amount of time specified on a student's behavior intervention plan.

b. When a principal or principal's designee has personal knowledge or actual notice of any of the events described in this subdivision, the principal or principal's designee shall promptly notify the student's parent or guardian and will provide the name of a school employee the parent or guardian can contact regarding the incident.

(3) As used in subdivision (2) of this subsection, "promptly notify" means by the end of the workday during which the incident occurred when reasonably possible, but in no event later than the end of following workday.

(4) The parent or guardian of the student shall be provided with a written incident report for any incident reported under this section within a reasonable period of time, but in no event later than 30 days after the incident. The written incident report shall include:

a. The date, time of day, location, duration, and description of the incident and interventions.
b. The events or events that led up to the incident.
c. The nature and extent of any injury to the student.
d. The name of a school employee the parent or guardian can contact regarding the incident.

(5) No local board of education or employee of a local board of education shall discharge, threaten, or otherwise retaliate against another employee of the board regarding that employee's compensation, terms, conditions, location, or privileges of employment because the employee makes a report alleging a prohibited use of physical restraint, mechanical restraint, aversive procedure,

or seclusion, unless the employee knew or should have known that the report was false.

(k) Nothing in this section shall be construed to create a private cause of action against any local board of education, its agents or employees, or any institutions of teacher education or their agents or employees or to create a criminal offense. (2005-205, s. 2; 2006-264, s. 58; 2011-282, s. 3.)

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Beverly Eaves Perdue, Governor

Albert A. Delia, Acting Secretary

November 13, 2012

MEMORANDUM

To: NC Instructor Trainers
NCI Instructors
Providers
LME Directors

From: Albert A. Delia

Re: Elimination of prone or face down position from crisis intervention techniques

The North Carolina Department of Health and Human Services (DHHS) remains committed to providing services and supports in a humane and safe environment that demonstrate respect for persons with disabilities, including individuals with mental health, developmental disabilities, and substance abuse needs. This is best accomplished with a workforce that is trained to prevent and avoid the use of physical interventions.

Following a recent tragic death at one of our facilities I verbally required that the use of prone restraints in our facilities be eliminated. This communication memorializes that instruction and expands the prohibition of the use of prone restraints to include both state facilities and community services. Today, I am issuing an immediate modification to the North Carolina Interventions (NCI) curriculum and program that updates any technique to eliminate the portion where a person ends up in a prone or face-down position. The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) staff will work with the NCI Quality Assurance Committee to implement this change as well as arrange and conduct training as appropriate. This modification also applies to all DMH/DD/SAS approved crisis intervention programs.

Since 1974, the state of North Carolina has recognized the need to train its workforce on techniques for dealing with crisis situations. The main focus has always been to prevent injury to the people we serve and the workforce while including methods that prevent and control crises as they occur.

The crisis prevention and intervention curriculum used in North Carolina have been updated to include best practices beginning in 1980 with the publication of A Better Way-Protective Intervention Techniques. In 1983, the curriculum, Basic Protective Intervention Techniques Manual (PIT) was adopted for use throughout the mental health, developmental disabilities and substance abuse service system. This curriculum was updated in 1984 and published as the Basic Protective Intervention Techniques Manual (PIC). PIC was used until 2001 when the curriculum was standardized to a core curriculum with an instructor trainer component that emphasized prevention and alternatives to restraint and seclusion.

This new curriculum, North Carolina Interventions (NCI), called for the implementation of a competency-based standardized and quality improved training program. Throughout the course of the NCI program there have been modifications made to the program as new best practices were identified and initiated.

In 2011, staff of the NC DHHS DMH/DD/SAS partnered with Appalachian State University (ASU) to review and make recommendations for a new NCI curriculum and crisis intervention program. While that work is scheduled to be completed in early 2014, DMH/DD/SAS staff will be working with the faculty of ASU to accelerate their efforts as much as possible without compromising the fidelity of their work in developing a new curriculum that has a stronger emphasis of prevention.

DMH/DD/SAS staff, the faculty at ASU, as well as the oversight committee working on this project have recommended the elimination of many of the existing optional techniques that allow for the use of the prone or face-down position in the new NCI curriculum. They have identified that the elimination of these optional techniques are a best practice and are in keeping with the philosophical direction of crisis intervention programs across the country. I strongly agree with this direction and work.

Questions should be directed to the NCI Program at DMH.NCI@dhhs.nc.gov.




RESTRAINT AND SECLUSION: RESOURCE DOCUMENT

U.S. Department of Education





This document was produced under U.S. Department of Education Contract No. ED-OSE-09-O-0058 with the American Institutes for Research. Renee Bradley served as the contracting officer's representative. This resource document contains websites and resources created by a variety of organizations. These websites and resources are provided for the user's convenience. No official endorsement by the U.S. Department of Education of any product, commodity, service or enterprise mentioned in this report or on websites referred to in this report is intended or should be inferred. The views expressed herein do not necessarily represent the positions or policies of the Department of Education and no official endorsement of them by the Department is intended or should be inferred.

U.S. Department of Education
Arne Duncan
Secretary

May 2012

This resource is available on the Department's Web site at: www.ed.gov/policy/restraintseclusion

On request, this publication is available in alternate formats, such as Braille, large print or compact disc.
For more information, contact the Department's Alternate Format Center at 202-260-0852 or 202-260-0818.

All photos are from Getty Images.

THE SECRETARY OF EDUCATION
WASHINGTON, DC 20202

May 15, 2012

As education leaders, our first responsibility must be to ensure that schools foster learning in a safe and healthy environment for all our children, teachers, and staff. To support schools in fulfilling that responsibility, the U.S. Department of Education has developed this document that describes 15 principles for States, school districts, schools, parents, and other stakeholders to consider when developing or revising policies and procedures on the use of restraint and seclusion. These principles stress that every effort should be made to prevent the need for the use of restraint and seclusion and that any behavioral intervention must be consistent with the child's rights to be treated with dignity and to be free from abuse. The principles make clear that restraint or seclusion should never be used except in situations where a child's behavior poses imminent danger of serious physical harm to self or others, and restraint and seclusion should be avoided to the greatest extent possible without endangering the safety of students and staff. The goal in presenting these principles is to help ensure that all schools and learning environments are safe for all children and adults.

As many reports have documented, the use of restraint and seclusion can have very serious consequences, including, most tragically, death. Furthermore, there continues to be no evidence that using restraint or seclusion is effective in reducing the occurrence of the problem behaviors that frequently precipitate the use of such techniques. Schools must do everything possible to ensure all children can learn, develop, and participate in instructional programs that promote high levels of academic achievement. To accomplish this, schools must make every effort to structure safe environments and provide a behavioral framework, such as the use of positive behavior interventions and supports, that applies to all children, all staff, and all places in the school so that restraint and seclusion techniques are unnecessary.

I hope you find this document helpful in your efforts to provide a world-class education to America's children. Thank you for all you do to support our schools, families, and communities and for your work on behalf of our nation's children.

Arne Duncan

Contents

Restraint and Seclusion: Resource Document **1**

Background **4**

Other Significant Federal Activity Regarding the Use of Restraint and Seclusion in Schools **6**

U.S. Government Accountability Office Report 6

Congressional Hearings and Proposed Legislation 7

Congressional Research Service Report 8

Terms Used in This Document **9**

The CRDC defines physical restraint as: 10

The CRDC defines mechanical restraint as: 10

The CRDC defines seclusion as: 10

Fifteen Principles **11**

Fifteen Principles 12

Federal Agency Efforts to Address Concerns **24**

Department of Education Efforts 25

Letters from the Secretary 25

Review of State Policies and Procedures 25

Office for Civil Rights 25

Office of Special Education Programs 26

Department of Health and Human Services Efforts 27

Children's Health Act 27

SAMHSA 28

Attachment A **29**

Attachment B **33**

Federal Resources 34

Associated Resources 36



Restraint and Seclusion: Resource Document[1]


School should be a safe and healthy environment in which America's children can learn, develop, and participate in instructional programs that promote high levels of academic achievement.

The foundation of any discussion about the use of restraint and seclusion is that every effort should be made to structure environments and provide supports so that restraint and seclusion are unnecessary. As many reports have documented, the use of restraint and seclusion can, in some cases, have very serious consequences, including, most tragically, death. There is no evidence that using restraint or seclusion is effective in reducing the occurrence of the problem behaviors that frequently precipitate the use of such techniques.

Physical restraint or seclusion should not be used except in situations where the child's behavior poses imminent danger of serious physical harm to self or others and restraint and seclusion should be avoided to the greatest extent possible without endangering the safety of students and staff. Schools should never use mechanical restraints to restrict a child's

freedom of movement.[2] In addition, schools should never use a drug or medication to control behavior or restrict freedom of movement unless it is (1) prescribed by a licensed physician, or other qualified health professional acting under the scope of the professional's authority under State law; and (2) administered as prescribed by the licensed physician or other qualified health professional acting under the scope of the professional's authority under State law. Teachers, administrators, and staff understand that students' social behavior can affect their academic learning. In many high-performing schools effective academic instruction is combined with effective behavior supports to maximize academic engagement and, thus, student achievement. Students are more likely to achieve when they are (1) directly taught school and classroom routines and social expectations that are predictable and contextually relevant; (2) acknowledged clearly and consistently for their displays of positive academic and social behavior; and (3) treated by

1 The U.S. Department of Education issues this Resource Document to provide guidance, and describe fifteen principles that States, school districts, school staff, parents, and other stakeholders may find helpful to consider when States, localities, and districts develop practices, policies, and procedures on the use of restraint and seclusion in schools. Our goal in providing this information is to inform States and school districts about how they can help to ensure that schools are safe learning environments for all students. As guidance, the extent to which States and school districts implement these principles in furtherance of that goal is a matter for State and local school officials to decide using their professional judgment, especially in applying this information to specific situations and circumstances. This document does not set forth any new requirements, does not create or confer any rights for or on any person or require specific actions by any State, locality, or school district.

We are interested in making this document as informative and useful as possible. If you are interested in commenting on this document, please e-mail your comments to Restraint.Seclusion@ed.gov or write to us at the following address: US Department of Education, 550 12th Street SW, PCP Room 4160, Washington, DC 20202-2600.

2 As the definition on page six of this document makes clear, "mechanical restraint" as used in this document does not include devices implemented by trained school personnel, or utilized by a student that have been prescribed by an appropriate medical or related services professional and are used for the specific and approved purposes for which such devices were designed.

others with respect. (Algozzine, R., Wang, C., and Violette, C., 2011; McIntosh, K., Chard, D., Boland, J., and Horner, R., 2006). Building effective behavioral supports in schools also involves several ongoing interrelated activities, including (1) investing in the whole school rather than just students with problem behavior; (2) focusing on preventing the development and occurrence of problem behavior; (3) reviewing behavioral data regularly to adapt school procedures to the needs of all students and their families; and (4) providing additional academic and social behavioral supports for students who are not making expected progress (Sugai, G., Horner, R., Algozzine, R., Barrett, S., Lewis, T., Anderson, C., Bradley, R., Choi, J. H., Dunlap, G., Eber, L., George, H., Kincaid, D., McCart, A., Nelson, M., Newcomer, L., Putnam, R., Riffel, L., Rovins, M., Sailor, W., Simonsen, B. (2010)).

Positive behavior interventions and supports (PBIS) is a multi-tiered school-wide approach to establishing the social culture that is helpful for schools to achieve social and academic gains while minimizing problem behavior for all children. Over 17,000 schools across the country are implementing PBIS, which provides a framework for decision-making that guides the implementation of evidence-based academic and behavioral practices throughout the entire school, frequently resulting in significant reductions in the behaviors that lead to office disciplinary referrals, suspensions, and expulsions. While the successful implementation of PBIS typically results in improved social and academic outcomes, it will not eliminate all behavior incidents in a school (Bradshaw, C., Mitchell, M., and Leaf, P. (2010); Muscott, H., and Mann, E. (in press); Lassen, S., Steele, M., and Sailor, W. (2006)). However, PBIS is an important preventive framework that can increase the capacity of school staff to support all children, including children with the most complex behavioral needs, thus reducing the instances that require intensive interventions.

Restraint or seclusion should not be used as routine school safety measures; that is, they should not be implemented except in situations where a child's behavior poses imminent danger of serious physical harm to self or others and not as a routine strategy implemented to address instructional problems or inappropriate behavior (e.g., disrespect, noncompliance, insubordination, out of seat), as a means of coercion or retaliation, or as a convenience.



Background



On July 31, 2009, Secretary of Education Arne Duncan sent a letter to Chief State School Officers stating that he was deeply troubled about the current use and effects of restraint and seclusion, which were the subject of testimony before the Education and Labor Committee in the U.S. House of Representatives' hearing examining the abusive and potentially deadly application of restraint and seclusion techniques in schools.

In his letter, Secretary Duncan encouraged each State to review its current policies and guidelines on the use of restraint and seclusion in schools to help ensure that every student is safe and protected, and, if appropriate, to develop or revise its policies and guidelines. In addition, Secretary Duncan urged the Chiefs to publicize these policies and guidelines so that administrators, teachers, and parents understand and consent to the limited circumstances under which these techniques may be used; ensure that parents are notified when these interventions occur; provide the resources needed to successfully implement the policies; and hold school districts accountable for adhering to the guidelines. The letter went on to highlight the use of PBIS as an important preventive approach that can increase the capacity of the school staff to support children with the most complex behavioral needs, thus reducing the instances that require intensive interventions.

Subsequently, the U.S. Department of Education (the Department) asked its regional Comprehensive Centers to collect each State's statutes, regulations, policies, and guidelines regarding the use of restraint and seclusion, and posted that information on the Department's Web site.[3] Additionally, the Department's Office for Civil Rights revised the *Civil Rights Data Collection* beginning with school year 2009-2010 to require reporting of the total number of students subjected to restraint or seclusion disaggregated by race/ethnicity, sex, limited English proficiency status, and disability, and to collect the total number of times that restraint or seclusion occurred.[4]

Additionally, in 2009, the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services (DHHS), asked the Department's Office of Special Education Programs (OSEP) to review a paper commissioned by SAMHSA (with the assistance of an expert work group) addressing the issue of restraint and seclusion in schools. Based on Secretary Duncan's letter to the Chief State School Officers and the experiences of SAMHSA with reducing, and in some cases eliminating, the use of restraint and seclusion in mental health facilities, the Department determined that it would be beneficial to all children if information and technical assistance were provided to State departments of education, local school districts, and preschool, elementary, and secondary schools regarding limiting the use of restraint and seclusion to situations involving imminent danger of serious physical harm to children or others.[5]

3 A revised version of that information is included in this document as Attachment A.

4 These data are available at http://ocrdata.ed.gov.

5 More detail about these efforts is included later in this document.

The purpose of this Resource Document is to present and describe 15 principles for State, district, and school staff; parents; and other stakeholders to consider when States, localities, and districts develop policies and procedures, which should be in writing on the use of restraint and seclusion. The principles are based on the nine principles that Secretary of Education Arne Duncan articulated in a 2009 letter to Chairman Christopher Dodd, Chairman George Miller, and Representative Cathy McMorris Rodgers in response to proposed legislation on restraint and seclusion. In his letter, the Secretary affirmed the Department's position that restraint and seclusion should not be used except when necessary to protect a child or others from imminent danger of serious physical harm. Since the Secretary issued his 2009 letter, the Department, working with the Department of Health and Human Services, further developed and refined the principles. The Department and the Department of Health and Human Services urge States, local districts, and schools to adopt policies that consider these 15 principles as the framework for the development and implementation of policies and procedures related to restraint and seclusion to help ensure that any use of restraint or seclusion in schools does not occur, except when there is a threat of imminent danger of serious physical harm to the student or others, and occurs in a manner that protects the safety of all children and adults at a school. The goal in presenting these principles is to help ensure that all schools and all learning environments are safe for all children and adults. This Resource Document discusses the context within which these principles were developed, lists the principles, and highlights the current state of practice and implementation considerations for each principle. Additionally, this document provides a synopsis of ongoing efforts by Federal agencies to address national concerns about using restraint and seclusion in schools. Two attachments at the end of this document provide information about State policies on the use of restraint and seclusion in our nation's public schools and an annotated resource guide on the use of restraint and seclusion in schools.

> In cases where a student has a history of dangerous behavior for which restraint or seclusion was considered or used, a school should have a plan for: (1) teaching and supporting more appropriate behavior; and (2) determining positive methods to prevent behavioral escalations that have previously resulted in the use of restraint or seclusion.

OTHER SIGNIFICANT FEDERAL ACTIVITY REGARDING THE USE OF RESTRAINT AND SECLUSION IN SCHOOLS

U.S. Government Accountability Office Report

The U.S. House of Representatives' Committee on Education and Labor requested the U.S. Government Accountability Office (GAO) to review the available evidence on the use of restraint and seclusion

that resulted in death and abuse at public and private schools and treatment centers. The GAO reviewed applicable Federal and State laws, interviewed knowledgeable State officials and recognized experts, and examined available evidence of abuse allegations from parents, advocacy organizations, and the media for the period between 1990 and 2009. These evidence reviews also involved the examination of selected closed cases, including police and autopsy reports and school policies on restraint or seclusion related to these cases.

The GAO report, titled *Examining the Abusive and Deadly Use of Seclusion and Restraint in Schools* (issued May 19, 2009), included three sets of findings. First, the GAO found that there were no current Federal regulations, but a wide variety of divergent State regulations, governing the use of restraint and seclusion in public and private schools. Second, the GAO reported that there were no reliable national data on when and how often restraint and seclusion are being used in schools, or on the extent of abuse resulting from the use of these practices in educational settings nationally. However, the GAO identified several hundred cases of alleged abuse, including deaths that were related to the use of restraint or seclusion of children in public and private schools. Finally, the GAO provided detailed documentation of the abuse of restraint or seclusion in a sample of 10 closed cases that resulted in criminal convictions, findings of civil or administrative liability, or a large financial settlement. The GAO further observed that problems with untrained or poorly trained staff were often related to many instances of alleged abuse.

Congressional Hearings and Proposed Legislation

The GAO report was presented to the U.S. House of Representatives' Committee on Education and Labor at a hearing on restraint and seclusion on May 19, 2009. Testimony at this and other hearings, together with related work by the Committee, led to the drafting of proposed Federal legislation on the use of restraint and seclusion in schools.

The 111th Congress considered legislation on the use of restraint and seclusion in schools. The House bill (H.R. 4247) was titled *Keeping All Students Safe Act*, and two Senate bills were introduced, *Preventing Harmful Restraint and Seclusion in Schools Act (S. 2860)* and *Keeping All Students Safe Act (S. 3895)*. In April, 2011, H.R. 4247 was reintroduced in the 112th Congress as H.R. 1381. And in December, 2011, S. 2020, *Keeping All Students Safe Act*, was introduced in the 112th Congress. The shared purposes of these bills were to (1) limit the use of restraint and seclusion in schools to cases where there

First, the GAO found that there were no current Federal regulations, but a wide variety of divergent State regulations, governing the use of restraint and seclusion in public and private schools.

is imminent danger of physical injury to the student or others at school; (2) provide criteria and steps for the proper use of restraint or seclusion; and (3) promote the use of positive reinforcement and other, less restrictive behavioral interventions in school. These measures also would have authorized support to States and localities in adopting more stringent oversight of the use of restraint and seclusion in schools, and would have established requirements for collecting data on the use of these practices in schools. Both the House and Senate bills were introduced and debated by their respective chambers in the 111th Congress, but only the House bill had passed when the Congressional session ended in December 2010. Therefore, no legislation related to restraint and seclusion in schools was enacted by the 111th Congress, nor has action on such legislation been taken, to date, in the 112th Congress.

Congressional Research Service Report

In October, 2010, the Congressional Research Service issued a report to Congress titled ***The Use of Seclusion and Restraint in Public Schools: The Legal Issues***. The report focused on the legal issues regarding the use of seclusion and restraint in schools, including their use with children covered by the Individuals with Disabilities Education Act (IDEA) and with children not covered by IDEA. The report addressed (1) definitions (*Civil Rights Data Collection* definitions); (2) constitutional issues; (3) IDEA judicial decisions related to seclusion and restraint; (4) State laws and policies; and (5) Federal legislation.

Terms Used In This Document

The Department's Office for Civil Rights (OCR) began collecting data on the use of restraint and seclusion in schools as part of the Department's 2009-2010 *Civil Rights Data Collection* (CRDC) and defined key terms related to restraint and seclusion.

References in this document to "restraint" encompass the terms "physical restraint" and "mechanical restraint" as defined in the CRDC. References to "seclusion" encompass "seclusion" as defined in the CRDC. According to the GAO report, each of these types of restraint is currently being used in schools.

The CRDC defines *physical restraint* as:

- A personal restriction that immobilizes or reduces the ability of a student to move his or her torso, arms, legs, or head freely. The term physical restraint does not include a physical escort. Physical escort means a temporary touching or holding of the hand, wrist, arm, shoulder, or back for the purpose of inducing a student who is acting out to walk to a safe location.

The CRDC defines *mechanical restraint* as:

- The use of any device or equipment to restrict a student's freedom of movement. This term does not include devices implemented by trained school personnel, or utilized by a student that have been prescribed by an appropriate medical or related services professional and are used for the specific and approved purposes for which such devices were designed, such as:
  - Adaptive devices or mechanical supports used to achieve proper body position, balance, or alignment to allow greater freedom of mobility than would be possible without the use of such devices or mechanical supports;
  - Vehicle safety restraints when used as intended during the transport of a student in a moving vehicle;
  - Restraints for medical immobilization; or
  - Orthopedically prescribed devices that permit a student to participate in activities without risk of harm.

The CRDC defines *seclusion* as:

- The involuntary confinement of a student alone in a room or area from which the student is physically prevented from leaving. It does not include a timeout, which is a behavior management technique that is part of an approved program, involves the monitored separation of the student in a non-locked setting, and is implemented for the purpose of calming.

A copy of the 2009-2010 CRDC and the OCR definitions of restraint and seclusion can be found at the following Web site: http://www2.ed.gov/about/offices/list/ocr/whatsnew.html. Restraint and seclusion data are available at http://ocrdata.ed.gov.[6]

6 As these terms are used in this document, "restraint" does not include behavioral interventions used as a response to calm and comfort (e.g., proximity control, verbal soothing) an upset student and "seclusion" does not include classroom timeouts, supervised in-school detentions, or out-of-school suspensions.

Fifteen Principles[7]

The Department, in collaboration with SAMHSA, has identified 15 principles that we believe States, local school districts, preschool, elementary, and secondary schools, parents, and other stakeholders should consider as the framework for when States, localities, and districts develop and implement policies and procedures, which should be in writing related to restraint and seclusion to ensure that any use of restraint or seclusion in schools does not occur, except when there is a threat of imminent danger of serious physical harm to the student or others, and occurs in a manner that protects the safety of all children and adults at school.

The Department recognizes that States, localities, and districts may choose to exceed the framework set by the 15 principles by providing additional protections from restraint and seclusion.

FIFTEEN PRINCIPLES

1. Every effort should be made to prevent the need for the use of restraint and for the use of seclusion.
2. Schools should never use mechanical restraints to restrict a child's freedom of movement, and schools should never use a drug or medication to control behavior or restrict freedom of movement (except as authorized by a licensed physician or other qualified health professional).
3. Physical restraint or seclusion should not be used except in situations where the child's behavior poses imminent danger of serious physical harm to self or others and other interventions are ineffective and should be discontinued as soon as imminent danger of serious physical harm to self or others has dissipated.
4. Policies restricting the use of restraint and seclusion should apply to all children, not just children with disabilities.
5. Any behavioral intervention must be consistent with the child's rights to be treated with dignity and to be free from abuse.

Every effort should be made to prevent the need for the use of restraint and for the use of seclusion.

6. Restraint or seclusion should never be used as punishment or discipline (e.g., placing in seclusion for out-of-seat behavior), as a means of coercion or retaliation, or as a convenience.
7. Restraint or seclusion should never be used in a manner that restricts a child's breathing or harms the child.
8. The use of restraint or seclusion, particularly when there is repeated use for an individual child, multiple uses within the same classroom, or multiple uses by the same individual, should trigger a review and, if appropriate, revision of strategies currently in place to address dangerous behavior;[8] if positive behavioral strategies are not in place, staff should consider developing them.
9. Behavioral strategies to address dangerous behavior that results in the use of restraint or seclusion should address the underlying cause or purpose of the dangerous behavior.
10. Teachers and other personnel should be trained regularly on the appropriate use of effective alternatives to physical restraint and seclusion, such as positive behavioral interventions and supports and, only for cases involving imminent danger of serious physical harm, on the safe use of physical restraint and seclusion.

7 This Resource Document addresses the restraint or seclusion of any student regardless of whether the student has a disability. Federal laws, including the IDEA, the Americans with Disabilities Act of 1990, as amended, and Section 504 of the Rehabilitation Act of 1973, as amended, must be followed in any instance in which a student with a disability is restrained or secluded, or where such action is contemplated. This Resource Document does not, however, address the legal requirements contained in those laws.

8 As used in this document, the phrase "dangerous behavior" refers to behavior that poses imminent danger of serious physical harm to self or others.

11. Every instance in which restraint or seclusion is used should be carefully and continuously and visually monitored to ensure the appropriateness of its use and safety of the child, other children, teachers, and other personnel.
12. Parents should be informed of the policies on restraint and seclusion at their child's school or other educational setting, as well as applicable Federal, State, or local laws.
13. Parents should be notified as soon as possible following each instance in which restraint or seclusion is used with their child.
14. Policies regarding the use of restraint and seclusion should be reviewed regularly and updated as appropriate.
15. Policies regarding the use of restraint and seclusion should provide that each incident involving the use of restraint or seclusion should be documented in writing and provide for the collection of specific data that would enable teachers, staff, and other personnel to understand and implement the preceding principles.

Following is additional information about each of the 15 principles.

1. **Every effort should be made to prevent the need for the use of restraint and for the use of seclusion.**

   All children should be educated in safe, respectful, and non-restrictive environments where they can receive the instruction and other supports they need to learn and achieve at high levels. Environments can be structured to greatly reduce, and in many cases eliminate, the need to use restraint or seclusion. SAMHSA notes in its *Issue Brief #1: Promoting Alternatives to the Use of Seclusion and Restraint*, that with leadership and policy and programmatic change, the use of seclusion and restraint can be prevented and in some facilities has been eliminated. One primary method is to structure the environment using a non-aversive effective behavioral system such as PBIS. Effective positive behavioral systems are comprehensive, in that they are comprised of a framework or approach for assisting school personnel in adopting and organizing evidence-based behavioral interventions into an integrated continuum that enhances academic and social behavioral outcomes for all students. The PBIS prevention-oriented framework or approach applies to all students, all staff, and all settings. When integrated with effective academic instruction, such systems can help provide the supports children need to become actively engaged in their own learning and academic success. Schools successfully implementing comprehensive behavioral systems create school-wide environments that reinforce appropriate behaviors while reducing instances of dangerous behaviors that may lead to the need to use restraint or seclusion. In

schools implementing comprehensive behavioral systems, trained school staff use preventive assessments to identify where, under what conditions, with whom, and why specific inappropriate behavior may occur, as well as implement de-escalation techniques to defuse potentially violent dangerous behavior. Preventive assessments should include (1) a review of existing records; (2) interviews with parents, family members, and students; and (3) examination of previous and existing behavioral intervention plans. Using these data from such assessments helps schools identify the conditions when inappropriate behavior is likely to occur and the factors that lead to the occurrence of these behaviors; and develop and implement preventive behavioral interventions that teach appropriate behavior and modify the environmental factors that escalate the inappropriate behavior. The use of comprehensive behavioral systems significantly decreases the likelihood that restraint or seclusion would be used, supports the attainment of more appropriate behavior, and, when implemented as described, can help to improve academic achievement and behavior.

2. **Schools should never use mechanical restraints to restrict a child's freedom of movement, and schools should never use a drug or medication to control behavior or restrict freedom of movement (except as authorized by a licensed physician or other qualified health professional).**

   Schools should never use mechanical restraints to restrict a child's freedom of movement. In addition, schools should never use a drug or medication to control behavior or restrict freedom of movement unless it is (1) prescribed by a licensed physician, or other qualified health professional acting under the scope of the professional's authority under State law; and (2) administered as prescribed by the licensed physician or other qualified health professional acting under the scope of the professional's authority under State law.

Schools should never use mechanical restraints to restrict a child's freedom of movement, and schools should never use a drug or medication to control behavior or restrict freedom of movement (except as authorized by a licensed physician or other qualified health professional).

3. **Physical restraint or seclusion should not be used except in situations where the child's behavior poses imminent danger of serious physical harm to self or others and other interventions are ineffective and should be discontinued as soon as imminent danger of serious physical harm to self or others has dissipated.**

   Physical restraint or seclusion should be reserved for situations or conditions where

there is imminent danger of serious physical harm to the child, other children, or school or program staff. These procedures should not be used except to protect the child and others from serious harm and to defuse imminently dangerous situations in the classroom or other non-classroom school settings (e.g., hallways, cafeteria, playground, sports field), and only should be used by trained personnel. Physical restraint or seclusion should not be used as a response to inappropriate behavior (e.g., disrespect, noncompliance, insubordination, out of seat) that does not pose imminent danger of serious physical harm to self or others, nor should a child be restrained and secluded simultaneously as this could endanger the child. In addition, planned behavioral strategies should be in place and used to: (1) de-escalate potentially violent dangerous behavior; (2) identify and support competing positive behavior to replace dangerous behavior; and (3) support appropriate behavior in class and throughout the school, especially if a student has a history of escalating dangerous behavior.

4. **Policies restricting the use of restraint and seclusion should apply to all children, not just children with disabilities.**

   Behavior that results in the rare use of restraint or seclusion -- that posing imminent danger of serious physical harm to self or others -- is not limited to children with disabilities, children with a particular disability, or specific groups of children (e.g., gender, race, national origin, limited English proficiency, etc.) without disabilities. Thus, to the extent that State and local policies address the use of restraint or seclusion, those policies, including assessment and prevention strategies, should apply to all children

in the school, all staff who work directly or indirectly with children, and across all settings under the responsibility of the school.

5. **Any behavioral intervention must be consistent with the child's rights to be treated with dignity and to be free from abuse.**

   Every child deserves to be treated with dignity, be free from abuse, and treated as a unique individual with individual needs, strengths, and circumstances (e.g., age, developmental level, medical needs). *The use of any technique that is abusive is illegal and should be reported to the appropriate authorities.* Schools should consider implementing an evidence-based school-wide system or framework of positive behavioral interventions and supports. Key elements of a school-wide system or framework include (1) universal screening to identify children at risk for behavioral problems; (2) use of a continuum of increasingly intensive behavioral and academic interventions for children identified as being at risk; (3) an emphasis on teaching and acknowledging school-wide and individual expected behaviors and social skills; and (4) systems to monitor the responsiveness of

individual children to behavioral and academic interventions. Increases in children's academic achievement and reductions in the frequency of disciplinary incidents can be realized when school-wide frameworks are implemented as designed and are customized to match the needs, resources, context, and culture of students and staff.

6. **Restraint or seclusion should never be used as punishment or discipline (e.g., placing in restraint for out-of-seat behavior), as a means of coercion, or retaliation, or as a convenience.**

   Restraint or seclusion should not be used as routine school safety measures; that is, they should not be implemented except in situations where a child's behavior poses imminent danger of serious physical harm to self or others and not as a routine strategy implemented to address instructional problems or inappropriate behavior (e.g., disrespect, noncompliance, insubordination, out of seat), as a means of coercion or retaliation, or as a convenience. Restraint or seclusion should only be used for limited periods of time and should cease immediately when the imminent danger of serious physical harm to self or others has dissipated. Restraint or seclusion should not be used (1) as a form of punishment or discipline (e.g., for out-of-seat behavior); (2) as a means to coerce, retaliate, or as a convenience for staff; (3) as a planned behavioral intervention in response to behavior that does not pose imminent danger of serious physical harm to self or others; or (4) in a manner that endangers the child. For example, it would be inappropriate to use restraint or seclusion for (1) failure to follow expected classroom or

   school rules; (2) noncompliance with staff directions; (3) the use of inappropriate language; (4) to "punish" a child for inappropriate behavior; or (5) staff to have an uninterrupted time together to discuss school issues.

7. **Restraint or seclusion should never be used in a manner that restricts a child's breathing or harms the child.**

   Prone (i.e., lying face down) restraints or other restraints that restrict breathing should never be used because they can cause serious injury or death. Breathing can also be restricted if loose clothing becomes entangled or tightened or if the child's face is covered by a staff member's body part (e.g., hand, arm, or torso) or through pressure to the abdomen or chest. Any restraint or seclusion technique should be consistent with known medical or other special needs of a child. School districts should be cognizant that certain restraint and seclusion techniques are more restrictive than others, and use the least restrictive technique necessary to end the threat of imminent danger of serious physical harm. A child's ability to communicate (including for those children who use only sign language or other

forms of manual communication or assistive technology) also should not be restricted unless less restrictive techniques would not prevent imminent danger of serious physical harm to the student or others. In all circumstances, the use of restraint or seclusion should never harm a child.

8. **The use of restraint or seclusion, particularly when there is repeated use for an individual child, multiple uses within the same classroom, or multiple uses by the same individual, should trigger a review and, if appropriate, a revision of behavioral strategies currently in place to address dangerous behavior; if positive behavioral strategies are not in place, staff should consider developing them.**

   In cases where a student has a history of dangerous behavior for which restraint or seclusion was considered or used, a school should have a plan for (1) teaching and supporting more appropriate behavior; and (2) determining positive methods to prevent behavioral escalations that have previously resulted in the use of restraint or seclusion. Trained personnel should develop this plan in concert with parents and relevant professionals by using practices such as functional behavioral assessments (FBAs) and behavioral intervention plans (BIPs). An FBA is used to analyze environmental factors, including any history of trauma (e.g., physical abuse), that contribute to a child's inappropriate (e.g., disrespect, noncompliance, insubordination, out-of-seat) behaviors. FBA data are used to develop positive behavioral strategies that emphasize redesigning environmental conditions, which may include changes in staff approaches and techniques, so that appropriate behavior is more likely to occur and inappropriate and dangerous behavior is less likely to occur.

   When restraint or seclusion is repeatedly used with a child, used multiple times within the same classroom, or used multiple times by the same individual, a review of the student's BIP should occur, the prescribed behavioral strategies should be modified, if needed; and staff training and skills should be re-evaluated. The need for the review is based on the individual needs of the child and the determination should include input from the family; a review could be necessitated by a single application of restraint or seclusion. This review may entail conducting another FBA to refine the BIP or examining the implementation of the current plan. If the student has a history of dangerous behavior and has been subjected to restraint or seclusion, a review and plan should be conducted prior to the student entering any program, classroom, or school. In all cases the reviews should consider not only the effectiveness of the plan, but also the capability of school staff to carry out the plan. Furthermore, if restraint or seclusion was used with a child who does not have an FBA and BIP, an FBA should be conducted and, if needed, a BIP developed and implemented that incorporates positive behavioral strategies for that child, including teaching positive behaviors. The long-term goal of FBAs and BIPs is to develop and implement preventive behavioral interventions, including increasing appropriate positive behaviors, that reduce the likelihood that restraint or seclusion will be used with a child in the future.

9. **Behavioral strategies to address dangerous behavior that results in the use of restraint or seclusion should address the underlying cause or purpose of the dangerous behavior.**

   Behavioral strategies, particularly when implemented as part of a school-wide program of positive behavioral supports, can be used to address the underlying causes of dangerous behavior and reduce the likelihood that restraint or seclusion will need to be used. Behavior does not occur in a vacuum but is associated with conditions, events, requirements, and characteristics of a given situation or setting. An FBA can identify the combination of antecedent factors (factors that immediately precede behavior)

   and consequences (factors that immediately follow behavior) that are associated with the occurrence of inappropriate behavior. Information collected through direct observations, interviews, and record reviews help to identify the function of the dangerous behavior and guide the development of BIPs. A complete BIP should describe strategies for (1) addressing the characteristics of the setting and events; (2) removing antecedents that trigger dangerous behavior; (3) adding antecedents that maintain appropriate behavior; (4) removing consequences that maintain or escalate dangerous behaviors; (5) adding consequences that maintain appropriate behavior; and (6) teaching alternative appropriate behaviors, including self regulation techniques, to replace the dangerous behaviors.

10. **Teachers and other personnel should be trained regularly on the appropriate use of effective alternatives to physical restraint and seclusion, such as positive behavioral interventions and supports and, only for cases involving imminent danger of serious physical harm, on the safe use of physical restraint and seclusion.**

    Positive behavioral strategies should be in place in schools and training in physical restraint and seclusion should first emphasize that every effort should be made to use positive behavioral strategies to prevent the need for the use of restraint and seclusion. School personnel working directly with children should know the school's policies and procedures for the safe use of physical restraint and seclusion, including both proper uses (e.g., as safety measures to address imminent danger of physical harm) and improper uses (e.g., as punishment or to manage behavior) of these procedures. In addition, school personnel should be trained in how to safely implement procedures for physical restraint and seclusion and only trained personnel should employ these interventions; as well as how to collect and analyze individual child data to determine the effectiveness of these procedures in increasing appropriate behavior and decreasing inappropriate behavior. These data

should inform the need for additional training, staff support, or policy change, particularly when data indicate repeated use of these interventions by staff.

School personnel also should receive training on the school's policies and procedures for the timely reporting and documentation of all instances in which restraint or seclusion are used. At a minimum, training on the use of physical restraint and seclusion and effective alternatives should be provided at the beginning and middle of each school year. However, such training should be conducted more often if there are enrolled students with a history or high incidence of dangerous behavior who may be subjected to physical restraint or seclusion procedures. In addition, school administrators should evaluate whether staff who engage in multiple uses of restraint or seclusion need additional training. All school personnel should receive comprehensive training on school-wide programs of positive behavioral supports and other strategies, including de-escalation techniques, for preventing dangerous behavior that leads to the use of restraint or seclusion. Training for principals and other school administrators should cover how to develop, implement, and evaluate the effectiveness of school-wide behavioral programs. Training for teachers, paraprofessionals, and other personnel who work directly with children should be ongoing and include refreshers on positive behavior management strategies, proper use of positive reinforcement, the continuum of alternative behavioral interventions, crisis prevention, de-escalation strategies, and the safe use of physical restraint and seclusion.

Behavioral strategies, particularly when implemented as part of a school-wide program of positive behavioral supports, can be used to address the underlying causes of dangerous behavior and reduce the likelihood that restraint or seclusion will need to be used.

Use and prevention training should be accompanied by regular supervised practice. Like quarterly fire drills, all staff members should be expected to regularly and frequently review and practice approaches to prevent the conditions that result in the use of restraint or seclusion and in the use of specific and planned physical restraint or seclusion procedures. A team of trained personnel should monitor practice sessions to check for adherence to and documentation of planned procedures.

11. **Every instance in which restraint or seclusion is used should be carefully and continuously and visually monitored to ensure the appropriateness of its use and the safety of the child, other children, teachers, and other personnel.**

    If restraint or seclusion is used, the child should be continuously and visually observed and monitored while he or she is restrained or placed in seclusion. Only school personnel who

have received the required training on the use of restraint and seclusion should be engaged in observing and monitoring these children. Monitoring should include a procedural checklist and recordkeeping procedures. School staff engaged in monitoring should be knowledgeable regarding (1) restraint and seclusion procedures and effective alternatives; (2) emergency and crisis procedures; (3) strategies to guide and prompt staff members engaged in restraint or seclusion procedures; and (4) procedures and processes for working as a team to implement, monitor, and debrief uses of restraint or seclusion. Monitoring staff should receive training to ensure that the use of physical restraint or seclusion does not harm the child or others, and that procedures are implemented as planned. For example, those observing the application of a restraint should confirm that the restraint does not cause harm to the child, such as restricting the child's breathing. Continuous monitoring of restraint includes, for example: (1) continuous assessment of staff and student status, including potential physical injuries; (2) termination of restraint or seclusion when imminent danger of serious physical harm to self or others has dissipated; (3) evaluation of how procedures are being implemented; and (4) consideration of opportunities for redirection and defusing the dangerous behavior. In developing procedures, States, districts, and schools should consider having school health personnel promptly assess the child after the imposition of restraints or seclusion.

Trained school staff should also inspect and prepare the seclusion area before a child is placed in seclusion. For example, the area should be free of any objects a child could use to injure him- or herself or others. School staff should either be inside the area or outside by a window or another adjacent location where staff can continuously observe the child and confirm that the child is not engaging in self-injurious behavior. When a child is in seclusion, trained school staff should constantly watch the child. Such observation and monitoring is critical in determining when the imminent danger of serious physical harm to self or others has dissipated so that the restraint or seclusion can be immediately discontinued. Proper observation and monitoring and written documentation of the use of restraint or seclusion helps to ensure the continued safety of the child being restrained or secluded as well as the safety of other children and school personnel.

12. **Parents should be informed of the policies on restraint and seclusion at their child's school or other educational setting, as well as applicable Federal, State or local laws.**

    All parents should receive, at least annually, written information about the policies and procedures for restraint and seclusion issued by the State, district, or school. This information should be included, for example, in the district's or school's handbook of policies and procedures or other appropriate and widely distributed school publications. Schools, districts, and States are encouraged to involve parents when developing policies and procedures on restraint and seclusion. These written descriptions should include the following: (1) a statement that mechanical restraint should not be used, that schools should never use a drug or medication to control behavior or restrict freedom of movement (except as authorized by a licensed

In addition, preventive strategies to reduce the likelihood that restraint or seclusion will need to be used with a child should be established, documented, and communicated to the child's parents.

physician or other qualified health professional), and physical restraint and seclusion should not be used except in situations where the child's behavior poses an imminent danger of serious physical harm to self or others and should be discontinued as soon as the imminent danger of serious physical harm to self or others has dissipated; (2) definitions of restraint and seclusion; (3) information on the procedures for determining when restraint or seclusion can and cannot be properly used in school settings; (4) information on the procedural safeguards that are in place to protect the rights of children and their parents; (5) a description of the alignment of a district's and school's policies and procedures with applicable State or local laws or regulations; (6) procedures for notifying parents when restraint or seclusion has been used with their child; and (7) procedures for notifying parents about any changes to policies and procedures on restraint or seclusion. If policy or procedural changes are made during the school year staff and family members should be notified immediately. In addition, preventive strategies to reduce the likelihood that restraint or seclusion will need to be used with a child should be established, documented, and communicated to the child's parents. Parents also should be encouraged to work with schools and districts to ensure planned behavioral strategies are in place and used to (1) de-escalate potentially violent dangerous behavior; (2) identify and support competing positive behavior to replace dangerous behavior; and (3) support appropriate behavior in class and throughout the school, especially if a student has a history of escalating dangerous behavior.

13. **Parents should be notified as soon as possible following each instance in which restraint or seclusion is used with their child.**

    Parents should be informed about the school's procedures for promptly notifying parents and documenting each time that restraint or seclusion is used with their child. The meaning of "as soon as possible" notification should be determined by the State, district, or school and included in the information on restraint and seclusion that is provided to parents. Documenting that parents have been notified as soon as possible, ideally on the same school day, when restraint or seclusion has been used ensures that parents are fully informed about their child's behavior and the school's response and helps parents participate as informed team members who can work with their child's teachers and other school staff to determine whether the behavioral supports at school and at home, including prevention and de-escalation strategies, are effective.

14. **Policies regarding the use of restraint and seclusion should be reviewed regularly and updated as appropriate.**

States, districts, and schools should not only establish and publish policies and procedures on the use of restraint and seclusion, but also should periodically review and update them as appropriate. This review should be conducted by a team (that includes parents) with expertise related to PBIS, and educating and supporting students with dangerous behaviors in schools and community settings. The review should consider and examine (1) available data on the use of these practices and their outcomes (i.e., the review should examine the frequency of the use of restraint and the use of seclusion across individual children, groups of children (e.g., gender, race, national origin, disability status and type of disability, limited English proficiency, etc.)), settings, individual staff, and programs and consider whether policies for restraint and seclusion are being applied consistently; (2) the accuracy and consistency with which restraint and seclusion data are being collected, as well as the extent to which these data are being used to plan behavioral interventions and staff training; (3) whether procedures for using these practices are being implemented with fidelity; (4) whether procedures continue to protect children and adults; and (5) whether existing policies and procedures for restraint and seclusion remain properly aligned with applicable State and local laws. The school should maintain records of its review of restraint and seclusion data and any resulting decisions or actions regarding the use of restraint and seclusion.

15. **Policies regarding the use of restraint and seclusion should provide that each incident involving the use of restraint or seclusion should be documented in writing and provide for the collection of specific data that would enable teachers, staff, and other personnel to understand and implement the preceding principles.**

Each incident of the use of restraint and of the use of seclusion should be properly documented for the main purposes of preventing future need for the use of restraint or seclusion and creating a record for consideration when developing a plan to address the student's needs and staff training needs. For example, a school should maintain a written log of incidents when restraint or seclusion is used. Appropriate school staff should prepare a written log entry describing each incident, including details of the child's dangerous behavior, why this behavior posed an imminent danger of serious physical harm to self or others, possible factors contributing to the dangerous behavior, the effectiveness of restraint or seclusion in de-escalating the situation and staff response to such behavior. Best practices and existing State policies and

procedures indicate that documentation of each use of restraint or seclusion frequently includes (1) start and end times of the restraint or seclusion; (2) location of the incident; (3) persons involved in the restraint or seclusion; (4) the time and date the parents were notified; (5) possible events that triggered the behavior that led to the restraint or seclusion; (6) prevention, redirection, or pre-correction strategies that were used during the incident; (7) a description of the restraint or seclusion strategies that were used during the incident; (8) a description of any injuries or physical damage that occurred during the incident; (9) how the child was monitored during and after the incident; (10) the debriefing that occurred with staff following the incident; (11) the extent to which staff adhered to the procedural implementation guidelines (if established by the State, district, or school); and (12) follow-up that will occur to review or develop the student's BIP.

For individual children, these data should be periodically reviewed to determine whether (1) there are strategies in place to address the dangerous behavior at issue; (2) the strategies in place are effective in increasing appropriate behaviors; and (3) new strategies need to be developed, or current strategies need to be revised or changed to prevent reoccurrences of the dangerous behavior(s).

Data on the frequency of use of restraint and seclusion for all children should be periodically reviewed at school leadership meetings, grade-level meetings, and other meetings of school staff. Data to be reviewed at these meetings should include information, consistent with privacy laws, about the frequency and duration of restraint and seclusion incidents across individual children, groups of children (e.g., gender, race, national origin, disability status and type of disability, limited English proficiency, etc.), settings, individual staff, and programs, as well as the number and proportion of children who were restrained or placed in seclusion since the last meeting and for the year to date. Such reviews should be used to determine whether state, district, and school policies are being properly followed, whether procedures are being implemented as intended, and whether the school staff should receive additional training on the proper use of restraint and seclusion or PBIS. States, districts, and schools should consider making these data public, ensuring that personally identifiable information is protected.

States, districts, and schools should not only establish and publish policies and procedures on the use of restraint and seclusion, but also should periodically review and update them as appropriate.

Federal Agency Efforts to Address Concerns

To date, Federal efforts to address concerns about the use of restraint and seclusion in schools have included the following four interrelated policy initiatives: (1) articulating principles to emphasize that physical restraint and seclusion should not be used except to protect a child or others from imminent danger of serious physical harm; (2) developing a dear colleague letter and this Resource Document that will be used to provide States, districts, and schools with information related to the proper and improper use of restraint and seclusion; (3) collecting, analyzing, and publishing restraint and seclusion incident data from every State; and (4) publishing State regulations, policies, and guidance on the use of restraint and seclusion.

A summary of these Federal efforts is presented below.

DEPARTMENT OF EDUCATION EFFORTS

Letters from the Secretary

Secretary of Education Arne Duncan issued two letters articulating the Department's position on the use of restraint and seclusion.

The first letter was sent to Chief State School Officers on July 31, 2009 urging each State to review its current policies and guidelines on the use of restraint and seclusion in schools, and, if appropriate, to develop or revise them to ensure the safety of students. The letter highlighted a school-wide system of PBIS as an important preventive approach that can increase the capacity of school staff to support children with complex behavioral needs, thus reducing the instances that require the use of restraint and seclusion. The letter also explained that the Department would be contacting each State to discuss the State's plans to ensure the proper use of restraint and seclusion to protect the safety of children and others at school.

On December 8, 2009, the Secretary sent a letter to Chairman Dodd, Chairman Miller, and Representative McMorris Rodgers. This letter expressed the Department's appreciation of Congressional efforts to limit the use of restraint and seclusion. The letter also articulated a list of nine principles that the Secretary believed would be useful for Congress to consider in the context of any legislation on restraint and seclusion. Additionally, the letter informed Congress that the Department was reviewing information about each State's laws, regulations, policies, and guidance on restraint and seclusion.

Review of State Policies and Procedures

The Department's Regional Comprehensive Technical Assistance Centers collected information on the policies and procedures on restraint and seclusion in each of the 50 States, eight territories, Bureau of Indian Education, and District of Columbia. These data were summarized and presented in a public report released in February 2010 and updated through a review of State Web sites in August 2011.

The first letter was sent to Chief State School Officers on July 31, 2009 urging each State to review its current policies and guidelines on the use of restraint and seclusion in schools, and, if appropriate, to develop or revise them to ensure the safety of students.

Office for Civil Rights

The Department's OCR enforces certain civil rights laws prohibiting discrimination on the basis of race, color, national origin, sex, and disability by recipients of Federal financial assistance from the Department and certain public entities. In September 2009, OCR announced in the *Federal Register* that it would include, for the first time, questions on restraint and seclusion in the *Civil Rights Data Collection (CRDC)*. The CRDC now collects school- and district-level information about students in public schools that includes (1) the number of

students by race/ethnicity, sex, Limited English Proficiency (LEP) status, and disability status subjected to physical restraint; (2) the number of students by race/ethnicity, sex, LEP status, and disability status subjected to mechanical restraint; (3) the number of students by race/ethnicity, sex, LEP status, and disability status subjected to seclusion; and (4) the total number of incidents of physical restraint, mechanical restraint, and seclusion by disability status. The data collection tables can be found at http://ocrdata.ed.gov/Downloads.aspx. The CRDC restraint and seclusion data are available at http://ocrdata.ed.gov. The data were released in two parts, in September 2011 and March 2012.

Office of Special Education Programs

OSEP has a long history of investments in national centers and projects that support school-wide behavioral frameworks in schools. Notably, in 1997, OSEP began funding the Technical Assistance Center on Positive Behavioral Interventions and Supports. The ongoing work of this center has led to the development and implementation of School-wide Positive Behavioral Interventions and Supports (SWPBIS). Now widely used throughout the country, SWPBIS is a framework for organizing evidence-based behavioral interventions into an integrated, multi-tiered continuum that maximizes academic and behavioral outcomes for all students.

SWPBIS is organized around six core principles: (1) invest first in the prevention of the social behavior that impedes student academic and social success in schools; (2) build a positive whole-school social culture by defining, teaching, and acknowledging clearly defined behavioral expectations for all students; (3) establish and apply consistently a continuum of consequences for problem behavior that prevents the inadvertent reward of problem behavior; (4) establish and apply consistently a multi-tiered continuum of evidence-based behavioral practices that supports behavioral success for all students, especially those students with more complex behavior support challenges; (5) collect and use data continuously to screen and monitor progress of all students, make instructional and behavioral decisions, and solve problems; and (6) invest in the organizational infrastructure and capacity to enable effective, efficient, and relevant implementation of evidence-based practices. These six core principles offer school administrators, teachers, and other school staff practical guidelines for implementing comprehensive behavioral systems that help prevent the need to use restraint and seclusion in school.

A growing body of evaluation and experimental research supports the following conclusions about the impact of SWPBIS implementation. Schools throughout the country are able to adopt and implement SWPBIS practices. When SWPBIS is implemented as intended, schools experienced reductions in problem behaviors (e.g., behavior that results in office referrals, suspensions). SWPBIS implementation enhances the impact of effective instruction on

academic outcomes. When SWPBIS is implemented as intended, students and staff members report improved school safety and organizational health. Furthermore, SWPBIS is sustainable when initial implementation is done as intended.

OSEP's Technical Assistance Center on PBIS has assisted States and local districts with the implementation of SWPBIS in over 17,000 schools across the United States. Each of these schools has a team that has gone through, or is going through, formal training on SWPBIS practices. Teams benefit from local coaching provided by district school psychologists, social workers, counselors, administrators, and special educators. States and districts have been successful in implementing and sustaining SWPBIS by actively and formally developing State, local, and school capacity for coordination, training, coaching, and evaluation. This capacity building, in turn, supports continual improvement, effective outcomes, and efficient and accurate implementation, and maximizes student academic and behavior outcomes for all students. The center's technical assistance supports participating local districts and schools in identifying, adopting, and sustaining SWPBIS effectively.

DEPARTMENT OF HEALTH AND HUMAN SERVICES EFFORTS

Children's Health Act

Although restraint and seclusion have been used in mental health settings and other medical facilities for many years, these practices have become more controversial because of tragic outcomes such as deaths and serious injuries. In 2000, Congress passed the Children's Health Act, which required DHHS to draft regulations under Title V of the Public Health Service Act for the use of restraint and seclusion in medical facilities and in residential non-medical community-based facilities for children and youth. The Act set minimum standards for the use of restraint and seclusion, which stipulate that (1) restraint and seclusion are crisis response interventions and may not be used except to ensure immediate physical safety and only after less restrictive interventions have been found to be ineffective; (2) restraint and seclusion may not be used for discipline or convenience; (3) mechanical restraints are prohibited; (4) restraint or seclusion may be imposed only by individuals trained and certified in their application; and (5) children being restrained or secluded must be continuously monitored during the procedure. The Children's Health Act also required DHHS to draft regulations for States to use in training individuals in facilities covered under the Federal law.[9]

9 Regulations implementing Part H (Requirements Relating to the Rights of Residents of Certain Facilities) of Title V of the Public Health Service (PHS) Act have been promulgated, although regulations implementing Part I (Requirements relating to the rights of Residents of Certain Non-Medical, Community-Based Facilities for Children and Youth) of Title V of the PHS Act have not yet been promulgated. Moreover, regulations have not been issued regarding training of facility staff.

The Children's Health Act of 2000 (CHA) (Pub. L. 106-310) amended title V of the PHS Act to add two new parts (Parts H and I) that established minimum requirements for the protection and the promotion of rights of residents of certain facilities to be free from the improper use of seclusion or restraint. Consistent with section 3207 of the Children's Health Act, the Centers for Medicare and Medicaid Services (CMS) issued regulations setting forth patient rights to be free of medically unnecessary restraint and seclusion in several types of health care facilities and programs, including: hospitals, in a final rule published at 71 Fed. Reg. 71378 (Dec. 8, 2006) that also applies to critical access hospitals; hospices, in a final rule published at 73 Fed. Reg. 32088 (June 5, 2008); Medicaid managed care, in a final rule published at 67 Fed. Reg. 40989 (June 14, 2002); programs of all-inclusive care for the elderly (PACE), in a final rule published at 71 Fed. Reg. 71244 (Dec. 8, 2006); and psychiatric residential treatment facilities for individuals under age 21, in an interim final rule published at 66 Fed. Reg. 7148 (Jan. 22, 2001). CMS has also proposed regulations governing the use of restraint and seclusion in Community Mental Health Centers, at 76 Fed. Reg. 35684 (June 17, 2011).

SAMHSA

As part of SAMHSA's continuing efforts to provide guidance on the Children's Health Act, in 2002, the agency developed the Six Core Strategies[10] model, which defines specific interventions to prevent or reduce the use of restraint and seclusion in healthcare settings. This model curriculum includes the following six core components:

- Leadership toward organizational change
- The use of data to inform practice
- Workforce Development: In-service training, supervision, and mentoring
- Use of primary prevention tools
- Supporting roles for persons served and advocates in programs
- Debriefing tools

While mainly used for training in healthcare settings, these six components have been found to be applicable in school settings. Furthermore, the policy concerns exemplified in these core components have contributed to the Department's interagency collaboration with SAMHSA to address the use of restraint and seclusion in school settings across the country.

10 NASMHPD published the first training curriculum on *Six Core Strategies© to Reduce the Use of Seclusion and Restraint in Inpatient Facilities* in 2002. Since then, the Six Core Strategies© have been formally evaluated, and the evidence indicates they likely meet criteria for inclusion on SAMHSA's National Registry of Evidence-Based Programs and Practices. http://www.grafton.org/Newsletter/art%20lebel.pdf

LeBel, J; Huckshorn, K.A.; Caldwell, B. (2010). *Restraint use in residential programs: Why are the best practices ignored?* Child Welfare 89(2), 169-187.



Attachment A

Revised Summary of Restraint and Seclusion Statutes, Regulations, Policies and Guidance, by State: Information as Reported to the Regional Comprehensive Centers and Gathered from Other Sources

This attachment is intended to be accessed through the Internet. If this document is being printed, pages 30-32 will not contain URLs.

State or District	Statutes and Regulations Addressing Restraint and Seclusion[+]	Policies and Guidance Addressing Restraint and Seclusion[x]
Alabama	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Alaska	Please see State Web site for further information.	No policies or guidance addressing seclusion and restraint.
Arizona	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Arkansas	Please see State Web site for further information.	Please see State Web site for further information.
California	Please see State Web site for further information.	Please see State Web site for further information.
Colorado	Please see State Web site for further information.	Please see State Web site for further information.
Connecticut	Please see State Web site for further information.	Please see State Web site for further information.
Delaware	Please see State Web site for further information.	Please see State Web site for further information.
District of Columbia	Please see District Web site for further information.	Please see District Web site for further information.
Florida	Please see State Web site for further information.	Please see State Web site for further information.
Georgia	Please see State Web site for further information.	Please see State Web site for further information.
Hawaii	Please see State Web site for further information.	Please see State Web site for further information.
Idaho*	Please see State Web site for further information.	Please see State Web site for further information.
Illinois	Please see State Web site for further information.	Please see State Web site for further information.
Indiana	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Iowa	Please see State Web site for further information.	Please see State Web site for further information.
Kansas	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Kentucky	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Louisiana*	Please see State Web site for further information.	No policies or guidance addressing seclusion and restraint.

State or District	Statutes and Regulations Addressing Restraint and Seclusion[+]	Policies and Guidance Addressing Restraint and Seclusion[x]
Maine	Please see State Web site for further information.	Please see State Web site for further information.
Maryland	Please see State Web site for further information.	Please see State Web site for further information.
Massachusetts	Please see State Web site for further information.	Please see State Web site for further information.
Michigan	Please see State Web site for further information.	Please see State Web site for further information.
Minnesota	Please see State Web site for further information.	Please see State Web site for further information.
Mississippi	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Missouri	Please see State Web site for further information.	Please see State Web site for further information.
Montana	Please see State Web site for further information.	Please see State Web site for further information.
Nebraska	Please see State Web site for further information.	Please see State Web site for further information.
Nevada	Please see State Web site for further information.	No policies or guidance addressing seclusion and restraint.
New Hampshire	Please see State Web site for further information.	Please see State Web site for further information.
New Jersey*	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
New Mexico	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
New York	Please see State Web site for further information.	Please see State Web site for further information.
North Carolina	Please see State Web site for further information.	Please see State Web site for further information.
North Dakota	Please see State Web site for further information.	No policies or guidance addressing seclusion and restraint.
Ohio	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Oklahoma*	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Oregon	Please see State Web site for further information.	Please see State Web site for further information.

State or District	Statutes and Regulations Addressing Restraint and Seclusion[+]	Policies and Guidance Addressing Restraint and Seclusion[x]
Pennsylvania	Please see State Web site for further information.	Please see State Web site for further information.
Rhode Island	Please see State Web site for further information.	Please see State Web site for further information.
South Carolina	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
South Dakota*	No state statute or regulations addressing seclusion and restraint.	No policies or guidance addressing seclusion and restraint.
Tennessee	Please see State Web site for further information.	Please see State Web site for further information.
Texas	Please see State Web site for further information.	Please see State Web site for further information.
Utah	Please see State Web site for further information.	No policies or guidance addressing seclusion and restraint.
Vermont	Please see State Web site for further information.	Please see State Web site for further information.
Virginia	Please see State Web site for further information.	Please see State Web site for further information.
Washington	Please see State Web site for further information.	Please see State Web site for further information.
West Virginia	No state statute or regulations addressing seclusion and restraint.	Please see State Web site for further information.
Wisconsin	Please see State Web site for further information.	Please see State Web site for further information.
Wyoming*	Please see State Web site for further information.	No policies or guidance addressing seclusion and restraint.

NOTE: In August 2009, the Regional Comprehensive Centers conducted research on each state's laws, regulations, guidance, and policies regarding the use of restraint and seclusion in schools and confirmed the information obtained with the states. The information in this report was updated by researchers at the American Institutes for Research in May 2012 and was current as of this date.

[+] Proposed or enacted laws and supporting regulations describing the implementation of the laws, originating from the State legislature.

[x] Statements or documents that set out the state views and expectations related to school district duties and responsibilities, originating from the State executive office.

[*] State restraint and seclusion statutes, regulations, policies, or guidance are still in development.



Attachment B



Restraint and Seclusion: Resource Document Resources with Annotations

This document contains links to Web sites and information created and maintained by public and private organizations other than the U.S. Department of Education. This information is provided for the reader's convenience. The U.S. Department of Education does not control or guarantee the accuracy, relevance, timeliness, or completeness of this outside information. Some of this information is presented as examples of information that may be relevant. Further, the inclusion of information or addresses, or Web sites for particular items does not reflect their importance, nor is it intended to endorse any views expressed, or products or services offered.

Federal Resources

Duncan, A. (2009, July 31). Letter from Education Secretary Arne Duncan to the Council of Chief State School Officers (CCSSO). Retrieved from http://www2.ed.gov/policy/elsec/guid/secletter/090731.html

In this letter to the CCSSO, Education Secretary Arne Duncan responds to the testimony issued by the Government Accountability Office on "Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers." He encourages the CCSSO to develop or review and, if appropriate, revise their State policies and guidelines to ensure that every student in every school under their jurisdiction is safe and protected from being unnecessarily or inappropriately restrained or secluded. He also urges them to publicize these policies and guidelines so that administrators, teachers, and parents understand and consent to the limited circumstances under which these techniques may be used; ensure that parents are notified when these interventions do occur; provide the resources needed to successfully implement the policies and hold school districts accountable for adhering to the guidelines; and to have the revised policies and guidance in place prior to the start of the 2009–2010 school year.

Duncan, A. (2009, December 8). Letter from Education Secretary Arne Duncan to Chairman Christopher J. Dodd, Chairman George Miller, and Representative Cathy McMorris Rodgers. Retrieved from http://www2.ed.gov/policy/gen/guid/secletter/091211.html

In this letter, Education Secretary Arne Duncan applauds the efforts of Chairman Christopher J. Dodd, Chairman George Miller, and Representative Cathy McMorris Rodgers to develop legislation to limit the use of physical restraint and seclusion in schools and other educational settings that receive Federal funds, except when it is necessary to protect a child or others from imminent danger. He reports that the U.S. Department of Education has identified a number of principles that may be useful for Congress to consider in the context of any legislation on this issue. These principles are listed in the letter.

The following legislation was introduced in the 111th and 112th Congresses, concerning limitations on the use of restraint and seclusion in schools and other educational settings:

- S. 2020, 112th Congress
- H.R. 1381, 112th Congress
- S. 3895, 111th Congress
- H.R. 4247, 111th Congress
- S. 2860, 111th Congress

Jones, N. L. & Feder, J. (2010). *The use of seclusion and restraint in public schools: The legal issues.* Washington, DC: Congressional Research Service. Retrieved from http://assets.opencrs.com/rpts/R40522_20101014.pdf

This research report was prepared by the Congressional Research Service for the members and committees of Congress. It was prepared because of congressional interest in the use of seclusion and restraint in schools, including passage of H.R. 4247 and the introduction of S. 2860, 111th Congress, first session. This report focuses on the legal issues concerning the use of seclusion and restraint in schools, including their application both to children covered by the

Individuals with Disabilities Education Act (IDEA) and to those not covered by IDEA. It refers to reports that document instances of deaths and injuries resulting from the use of seclusion or restraints in schools. This report notes that the IDEA requires a free appropriate public education for children with disabilities, and an argument could be made that some uses of seclusion and restraint would violate this requirement. The passage of S. 2860 in the Senate would establish minimum safety standards in schools to prevent and reduce the inappropriate use of restraint and seclusion.

Kutz, G. D. (2009). *Seclusions and restraints: Selected cases of death and abuse at public and private schools and treatment centers.* (GAO-09-719T). Washington, DC: U.S. Government Accountability Office, Forensic Audits and Special Investigations. Retrieved from http://www.gao.gov/new.items/d09719t.pdf

This report addresses the recent testimony of the Government Accountability Office (GAO) before the Congressional Committee on Education and Labor regarding allegations of death and abuse at residential programs for troubled teens. It cites other reports that indicate that vulnerable children are being abused in other settings, through the use of restraint and seclusion in schools. This report provides an overview of seclusion and restraint laws applicable to children in public and private schools, discusses whether allegations of student death and abuse from the use of these methods are widespread, and examines the facts and circumstances surrounding cases in which a student died or suffered abuse as a result of being secluded or restrained. The report is a review of Federal and State laws and abuse allegations from advocacy groups, parents, and the media from the past two decades. The report found no Federal law restricting the use of seclusion and restraint, and found hundreds of cases of alleged abuse and death related to the use of these methods on school children; examples are provided.

U.S. Department of Education. (2010) *Summary of seclusion and restraint statutes, regulations, policies and guidance, by State and territory: Information as reported to the regional Comprehensive Centers and gathered from other sources.* Washington, DC: Author. Retrieved from http://www2.ed.gov/policy/seclusion/seclusion-state-summary.html

This summary documents the results of the Department of Education's 2009 request that the States report on their laws, regulations, guidance, and policies regarding the use of seclusion and restraints in schools. The document includes the descriptive information as verified by each State and territory, and a summary of this information.

U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration Jan Lebel (2011) *The business case for preventing and reducing restraint and seclusion use.* Washington, DC: Retrieved from http://store.samhsa.gov/shin/content//SMA11-4632/SMA11-4632.pdf

This document asserts that restraint and seclusion are violent, expensive, largely preventable, adverse events. The document also makes a number of claims, including the following: (1) the rationale for the use of restraint and seclusion is inconsistently understood and contribute to a cycle of workplace violence that can reportedly claim as much as 23 to

50 percent of staff time, account for 50 percent of staff injuries, increase the risk of injury to consumers and staff by 60 percent, and increase the length of stay, potentially setting recovery back at least 6 months with each occurrence; (2) restraint and seclusion increases the daily cost of care and contributes to significant workforce turnover reportedly ranging from 18 to 62 percent, costing hundreds of thousands of dollars to several million; (3) restraint and seclusion procedures raise the risk profile to an organization and incur liability expenses that can adversely impact the viability of the service; (4) many hospitals and residential programs, serving different ages and populations, have successfully reduced their use and redirected existing resources to support additional staff training, implement prevention-oriented alternatives, and enhance the environment of care; and (5) significant savings result from reduced staff turnover, hiring and replacement costs, sick time, and liability-related costs.

Associated Resources

American Association of School Administrators. (2010, March 2). Letter to U.S. House of Representatives. Retrieved from http://www.aasa.org/uploadedFiles/Policy_and_Advocacy/files/HR4247LetterMarch2010.pdf

In this letter to the U.S. House of Representatives, the American Association of School Administrators (AASA) urges the House not to pass restraint and seclusion measure H.R. 4247. The AASA states that the need to establish these particular Federal regulations for seclusion and restraint has not been established by objective, carefully gathered and analyzed data, and that the voices of teachers and administrators have not been heard. The letter notes that the Office for Civil Rights within the U.S. Department of Education is preparing to gather more objective information, and asks the House to wait for these objective results. The AASA also describes the report recently released by the U.S. Department of Education, which confirms that 31 States already have policies in place to oversee the use of seclusion and restraint and 15 more are in the process of adopting policies and protections. Given this substantial State action, AASA questions the need for Federal involvement on this issue. Finally, the letter protests the tone of H.R. 4247, which it describes as relentlessly negative toward teachers and administrators.

The Council for Children with Behavioral Disorders. (2009). *Physical restraint and seclusion procedures in school settings.* Arlington, VA: Council for Exceptional Children. Retrieved from http://www.ccbd.net/sites/default/files/CCBD%20Summary%20on%20Restraint%20and%20Seclusion%207-8-09.pdf

This document is a summary of policy recommendations from two longer and more detailed documents available from the Council for Children with Behavioral Disorders (CCBD) regarding the use of physical restraint and seclusion procedures in schools. CCBD is the division of the Council for Exceptional Children (CEC) committed to promoting and facilitating the education and general welfare of children and youth with emotional or behavioral disorders. In this document, CCBD states that while restraint and seclusion can be effective when dealing with children with behavioral issues, they should not be implemented except as a last resort when a child or others are in immediate danger. CCBD further recommends that new legislation or regulations be established to formally require that data on restraint and seclusion be reported to outside agencies, such as State or provincial departments of education.

The document also notes that additional research is needed on the use of physical restraint and seclusion with children or youth across all settings.

Dunlap, G., Ostryn, C., & Fox, L. (2011). *Preventing the Use of Restraint and Seclusion with Young Children: "The Role of Effective, Positive Practices". Issue Brief.* Technical Assistance Center on Social Emotional Intervention for Young Children. University of South Florida, 13301 North Bruce B Downs Boulevard MHC2-1134, Tampa, FL 33612. Web site: http://www.challengingbehavior.org. Retrieved from http://www.eric.ed.gov/ERICWebPortal/contentdelivery/servlet/ERICServlet?accno=ED526387

The purpose of this document is to review what constitutes restraint and seclusion, what should be done as an alternative, and discuss positive strategies that can be used to prevent behaviors that could lead to considerations of these invasive and potentially-dangerous practices.

Hague, B. (2010, February 18). *Stricter standards sought for use of seclusion and restraint by schools.* (Recording). Wisconsin Radio Network. Retrieved from http://www.wrn.com/2010/02/stricter-standards-sought-for-use-of-seclusion-and-restraint-by-schools/

This interview discusses a Wisconsin State capitol hearing on how best to deal with students with special needs who become disruptive. The organization, Disability Rights Wisconsin, claims that the State's department of education is not doing enough to curtail excessive use of restraint and seclusion; the State department of education disagrees. The interview reports that the State Senate is discussing legislation to restrict the use of restraint and seclusion, but the department of education is arguing that this legislation will go too far and prevent teachers and administrators from maintaining a safe classroom. The Senate intends to require that all teachers and other personnel be required to receive training in PBIS to reduce the need for seclusion and restraint, and claims that this will make schools safer and improve academic performance. The piece also notes concerns about the costs to districts of implementing additional training, as well as potential lawsuits.

Horner, R. & Sugai, G. (2009). *Considerations for seclusion and restraint use in school-wide positive behavior supports.* Eugene, OR: OSEP Technical Assistance Center on Positive Behavioral Interventions and Support. Retrieved from http://www.pbis.org/common/pbisresources/publications/Seclusion_Restraint_inBehaviorSupport.pdf

The PBIS Center defines seclusion and restraint as safety procedures in which a student is isolated from others (seclusion) or physically held (restraint) in response to serious problem behavior that places the student or others at risk of injury or harm. This document expresses concern regarding these procedures being prone to misapplication and abuse, potentially placing students at equal or more risk than their problem behavior. The specific concerns are listed and recommendations are made to promote effective policies. School-wide positive behavior support (SWPBS) is one of the major recommendations, defined as a systems approach to establishing the whole-school social culture and intensive individual behavior supports needed for schools to achieve social and academic gains while minimizing problem

behavior for all students. SWPBS emphasizes four integrated elements: socially valued and measurable outcomes, empirically validated and practical practices, systems that efficiently and effectively support implementation of these practices, and continuous collection and use of data for decision-making. These elements are described in detail along with supporting research.

The Legal Center for People with Disabilities and Older People. (2007). *Public report of an investigation into the improper use of restraint and/or seclusion of students with disabilities at Will Rogers elementary school.* Denver, CO: Author. Retrieved from http://66.147.244.209/~tashorg/wp-content/uploads/2011/01/The-Legal-Center_PA-Investigation.pdf

The Legal Center for People with Disabilities and Older People (the Legal Center) is the Protection and Advocacy System for Colorado. This report presents the results of the investigation conducted by the Legal Center into the circumstances surrounding the use of seclusion and restraint of five elementary school students. The Legal Center received complaints that students with a range of emotional, mental health, and developmental disabilities were subjected to improper use of restraint and seclusion by school staff at Will Rogers Elementary School. The information produced in the course of this investigation supports the conclusion that the five students were repeatedly subjected to improper restraint and seclusion in violation of the Colorado Department of Education restraint/seclusion rules. Based on this, the Legal Center recommends a number of actions be taken by District 11 and staff at Will Rogers Elementary school.

Morrison, L. & Moore, C. (2007). *Restraint and seclusion in California schools: A failing grade.* Oakland, CA: Protection & Advocacy, Inc. (PAI). Retrieved from http://www.disabilityrightsca.org/pubs/702301.htm

PAI conducted an in-depth investigation into allegations of abusive restraint and seclusion practices involving seven students in five public schools and one non-public school in California. The investigations revealed both the failure of school personnel to comply with existing regulations and the inability of current law to sufficiently regulate the use of these dangerous practices. PAI released this report to reinforce compliance with current regulatory requirements and to challenge schools and the education system to bring standards regarding behavioral restraint and seclusion of students into line with current practices in all other settings. The report notes that there are strict guidelines limiting the use of restraint and seclusion to extreme situations where there is an imminent risk of serious physical harm to an individual and only for the duration and to the extent necessary to protect the individual.

National Association of State Mental Health Program Directors (NASMHPD): Huckshorn, K. (2005). *Six core strategies to reduce the use of seclusion and restraint planning tool.* Retrieved from http://www.hogg.utexas.edu/uploads/documents/SR_Plan_Template.pdf

This planning tool guides the design of a seclusion and restraint reduction plan that incorporates the use of a prevention approach, includes six core strategies to reduce the use of seclusion and restraint described in the NASMHPD curriculum, and ascribes to the principles of continuous quality improvement. It

may also be used as a monitoring tool to supervise implementation of a reduction plan and identify problems, issues barriers and successes.

National Disability Rights Network. (2009, January). *School is not supposed to hurt: Investigative report on abusive restraint and seclusion in schools.* Retrieved from http://www.napas.org/images/Documents/Resources/Publications/Reports/SR-Report2009.pdf (Updated in 2010)

This report is divided into two sections. The first identifies the problems attributed to restraint or seclusion. It includes a "Chronicle of Harm" detailing treatment of children of all ages and in every corner of the nation – urban, suburban, and rural, in wealthy and poor school districts, as well as in private schools. It outlines the problems associated with the use of restraint or seclusion, and details the proven risks to children associated with the use of these aversive techniques. Contributing factors are identified, such as the lack of appropriate training for teachers and other school personnel in the use of positive behavioral supports that address children's behavioral and other issues in a humane and effective way.

The second section of this report proposes solutions to the use of restraint or seclusion by highlighting the best practices in education and the use of positive behavioral supports. Included is a catalogue of advocacy activities that have been undertaken by P&As to protect children with disabilities. These activities range from educating parents, students, and school personnel, to investigating and litigating when abuses occur, to working for strong State and federal laws to protect these vulnerable children. An update to this report and follow-up letter are available at: National Disability Rights Network, Not Supposed to Hurt: Update on Progress in 2009, at http://ndrn.org/images/Documents/Resources/Publications/Reports/School-is-Not-Supposed-to-Hurt-NDRN.pdf

National Disability Rights Network, School Is Not Supposed to Hurt: The U.S. Department of Education Must Do More to Protect School Children from Restraint and Seclusion, March 2012, *at* http://ndrn.org/images/Documents/Resources/Publications/Reports/School_is_Not_Supposed_to_Hurt_3_v7.pdf

Samuels, C. A. (2009). Use of seclusion, restraints on students at issue: Watchdog agency preparing report on practices. *Education Week, 28*(29), 6. Retrieved from http://www.edweek.org/ew/articles/2009/04/17/29restrain.h28.html

This article reports that many States lack policies related to seclusion or restraint in schools, and that the Federal government does not require record-keeping on the practices. The article details the efforts of advocacy groups for people with disabilities to keep the issue of restraint and seclusion as a priority for the Federal government and the national media. Organizations are trying to get Federal economic stimulus funds as a source of money to pay for the professional development that they say would foster a positive school environment. Advocates believe that such training for educators would prevent problems from escalating to the point that secluding students or physically restraining them is needed. Advocates, as well as educational organizations, agree that more training is necessary to reduce the use of restraint and seclusion in school. The article presents a discussion by several organizations' representatives on ways to provide this training.

Shank, C., Greenberg, J., & Lebens, M. (2011). *Keep school safe for everyone: A report on the restraint and seclusion of children with disabilities in Oregon schools.* Portland, OR: Disability Rights Oregon is the Protection & Advocacy System for Oregon. Retrieved from http://www.disabilityrightsoregon.org/results/DRO-Keep%20School%20Safe%20for%20Everyone%20Report.pdf

The Disability Rights Oregon (DRO) gathered information from parents and schools about the use of physical restraint and seclusion in Oregon and provided policy recommendations on the use of these practices in the State. The DRO report found that the use of physical restraint and seclusion varied considerably across Oregon school districts. For example, some Oregon districts had adopted appropriate policies and were trying to follow them. Other districts, however, had not adopted any policies at all. Furthermore, many Oregon districts were found to have policies that were inconsistent with their own administrative rules. This report also details stories of Oregon children who were restrained and secluded and had experienced psychological and physical injuries resulting from the use of these practices at school. In addition, the report provides a list of policy recommendations on physical restraint and seclusion. The report notes that its recommended policies are generally consistent with policies contained in Federal legislation. The DRO concludes that its recommended policies will provide enforceable minimum safety standards, provide administrative review and independent oversight, and help make Oregon's schools safe for all students and staff.

Southern Tier Independence Center, Disabled Abuse Coalition. (2009). *Abuse and neglect of children with disabilities in New York non-residential public schools.* Binghamton, NY: Author. Retrieved from http://www.ndrn.org/images/Documents/Issues/Restraint_and_Seclusions/NDRN_Children_with_Disabilities_2009.pdf

This document responds to reports by families and advocates indicating a pattern of discriminatory treatment toward children with disabilities who are neglected or abused in non-residential public schools in New York. The document notes that, under New York law, these schools are allowed to use physical restraints, including straps, "take-downs," and "time-out rooms," for unlimited periods of time as punishment for minor infractions, including any behavior that may "disrupt the order of the school." However, such restraints are often used by poorly trained staff, and the potential for serious injury is high. The document states that experts in special education universally agree that restraints should not be used except as emergency measures for children who are immediately and seriously dangerous to themselves or others, and that use of restraints under those circumstances should trigger an immediate comprehensive response to investigate antecedents to the problem behavior and develop proactive plans to address it. Thus, the STIC argues that New York State needs to enact stringent legislation to regulate the use of physical restraint, provide training requirements for public non-residential school aides that are strictly enforced, and empower State and local police and child-protective authorities to immediately accept and promptly investigate all complaints of abuse and neglect and to file criminal charges when warranted.

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

The Ins & Outs of Intake:
Resources for People with Disabilities

Contents

- PowerPoint Presentation Handout
- DRNC 2019 Targets

THE INS & OUTS OF INTAKE RESOURCES FOR PEOPLE WITH DISABILITIES

INFORMATION & REFERRAL

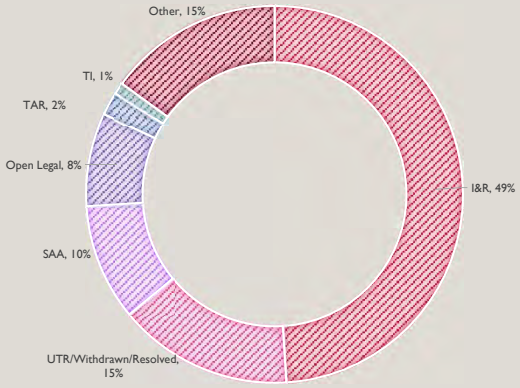
IN THE PAST YEAR… APRIL 1, 2018-MARCH 31, 2019

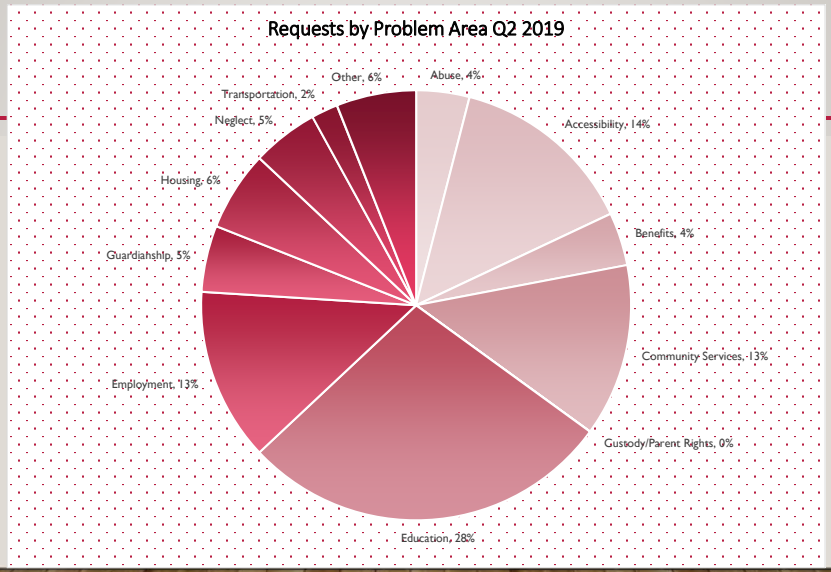
Total service requests sent to Intake Team: 743

TOP 10 COUNTIES

Wake	18%
Mecklenburg	9%
Durham	6%
Guilford	4%
Buncombe	3%
Cumberland	3%
Johnston	3%
Forsyth	2%
Orange	2%
Pitt	2%

METHODS FOR HANDLING SR REQUESTS, Q2 2019





WHAT HAPPENS WHEN YOU CALL US?

The Call

When you call Disability Rights NC, the receptionist will ask you a few screening questions.

1. What are you needing assistance with?

2. Do you or does the person you are calling about have a disability?

3. If you are not the person with a disability, are you the parent of a minor child with a disability or the Legal Guardian/POA of a person with a disability?

If your problem falls under one of our Targets, you will be forwarded to an Intake Specialist. If not, our Receptionist will provide you with the appropriate resources.

The Interview

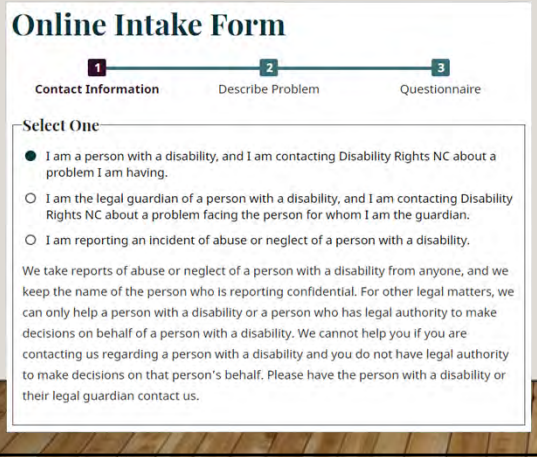
The Intake Specialist will collect information based on the target criteria relevant to your situation and forward to the appropriate team.

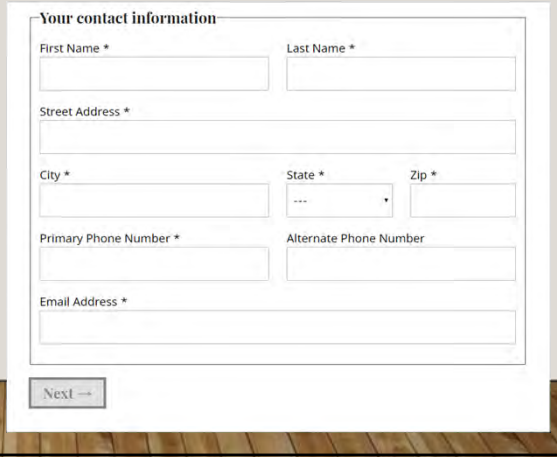
After the Interview

An attorney will review the information. If they determine that we can assist you directly, you will be contacted by an attorney or advocate. Otherwise, the Intake Specialist will provide you with self-advocacy information or referrals.

WHAT HAPPENS WHEN YOU FILL OUT AN ONLINE INTAKE FORM?

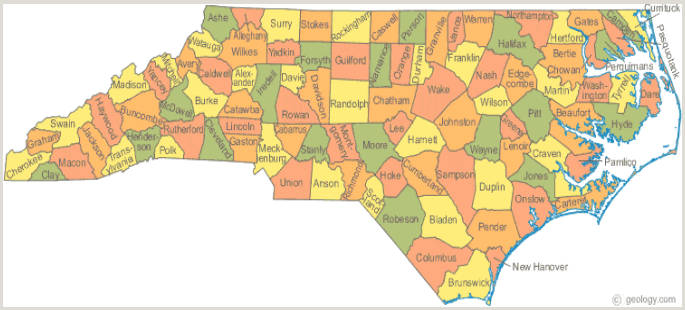
Once you submit your intake form, it will automatically be sent to our general email box.





COMMUNITY OUTREACH

An ongoing effort and goal of the Intake Team is to reach more of the underserved and vulnerable populations in North Carolina- by building partnerships with other agencies, identifying what needs aren't being met, and expanding our presence in rural areas.



DISABILITY RIGHTS NORTH CAROLINA

2019 Targets and Monitoring Work

Each year, Disability Rights North Carolina adopts a plan to focus its work on the greatest threats to the independence of people with disabilities and the most prevalent violations of disability rights laws. This plan includes Targets.

What Is a Target?

To achieve full equality and justice for people with disabilities, we need to accomplish many different goals. But we do not have the resources to tackle all of those goals at one time.

Through public input and our work with clients, we identify problems that are widespread and threaten the independence of people with disabilities. Then we develop Targets to address those problems.

Why Do We Need Targets?

Disability Rights NC is the federally mandated Protection and Advocacy (P&A) system in North Carolina. Most of our funding comes from the federal government, which requires Targets. Our Targets guide the work of our legal teams and provide the structure within which we spend our limited resources.

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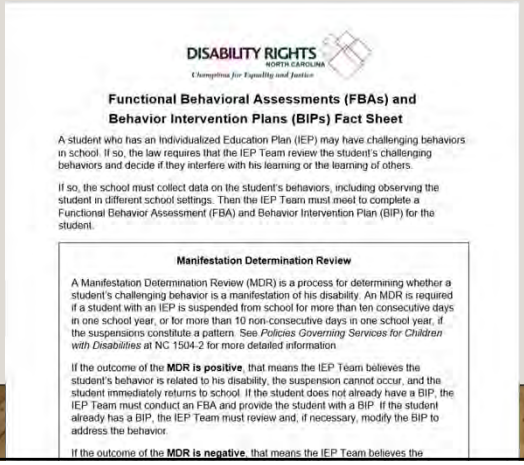
CAROLINA
EDUCATION, PRISONS & JAILS

Target 1. Keep students with disabilities in school.



DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

Functional Behavioral Assessments (FBAs) and Behavior Intervention Plans (BIPs) Fact Sheet

A student who has an Individualized Education Plan (IEP) may have challenging behaviors in school. If so, the law requires that the IEP Team review the student's challenging behaviors and decide if they interfere with his learning or the learning of others.

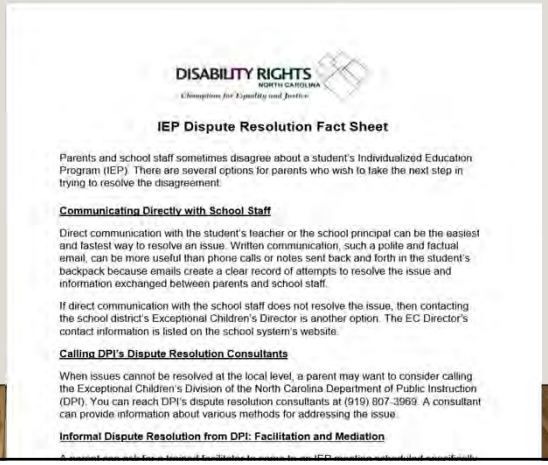
If so, the school must collect data on the student's behaviors, including observing the student in different school settings. Then the IEP Team must meet to complete a Functional Behavior Assessment (FBA) and Behavior Intervention Plan (BIP) for the student.

Manifestation Determination Review

A Manifestation Determination Review (MDR) is a process for determining whether a student's challenging behavior is a manifestation of his disability. An MDR is required if a student with an IEP is suspended from school for more than ten consecutive days in one school year, or for more than 10 non-consecutive days in one school year, if the suspensions constitute a pattern. See *Policies Governing Services for Children with Disabilities* at NC 1504-2 for more detailed information.

If the outcome of the **MDR is positive**, that means the IEP Team believes the student's behavior is related to his disability, the suspension cannot occur, and the student immediately returns to school. If the student does not already have a BIP, the IEP Team must conduct an FBA and provide the student with a BIP. If the student already has a BIP, the IEP Team must review and, if necessary, modify the BIP to address the behavior.

If the outcome of the **MDR is negative**, that means the IEP Team believes the



DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

IEP Dispute Resolution Fact Sheet

Parents and school staff sometimes disagree about a student's Individualized Education Program (IEP). There are several options for parents who wish to take the next step in trying to resolve the disagreement.

Communicating Directly with School Staff

Direct communication with the student's teacher or the school principal can be the easiest and fastest way to resolve an issue. Written communication, such a polite and factual email, can be more useful than phone calls or notes sent back and forth in the student's backpack because emails create a clear record of attempts to resolve the issue and information exchanged between parents and school staff.

If direct communication with the school staff does not resolve the issue, then contacting the school district's Exceptional Children's Director is another option. The EC Director's contact information is listed on the school system's website.

Calling DPI's Dispute Resolution Consultants

When issues cannot be resolved at the local level, a parent may want to consider calling the Exceptional Children's Division of the North Carolina Department of Public Instruction (DPI). You can reach DPI's dispute resolution consultants at (919) 807-3969. A consultant can provide information about various methods for addressing the issue.

Informal Dispute Resolution from DPI: Facilitation and Mediation

Target 8. Investigate and report on the safety of people with MI admitted to our jails.

Target 9. Ensure appropriate treatment for people with disabilities in NC prisons.

DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

Requesting a Reasonable Accommodation in Prison

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act apply to public entities, including prisons. These laws prevent a prison from discriminating against any qualified person with a disability in accessing the prison's jobs, programs, activities or services.

One way to prevent discrimination is by giving a reasonable accommodation – making a change to the environment or procedures so that a qualified person with a disability can use the program, service or job. Prison officials may recognize that you need a reasonable accommodation. You can also request an accommodation.

How to Request a Reasonable Accommodation

1. Ask your Case Manager or Mental Health Social Worker for an Inmate Reasonable Accommodation Request (IRAR) form. This is form DC-746.
2. Fill out the form (or have your guardian fill it out) and return it to your Case Manager.
3. Your Case Manager will give the form to the prison ADA Coordinator for review.
4. The prison ADA coordinator will send the form to state Prisons ADA Coordinator and the Prisons ADA Compliance Specialist for final approval.

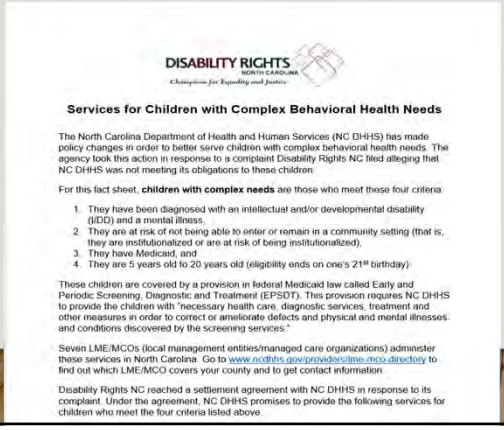
You will receive the state's decision within 45 working days of your request. The state can

KARLA
FACILITIES, EMERGENCY/DISASTER MANAGEMENT, CHILDREN WITH COMPLEX NEEDS, COMMUNITY ACCESS

Target 5. Reduce NC's over-reliance on PRTFs and ensure that the state shift resources to support community-based services for youth.

Emergency/Disaster Management: Ensure that evacuees with disabilities have the supports and services they need while in shelters, as they transition home, and when they return home.

Ongoing monitoring efforts for Children with Complex Needs, ensuring they receive services and supports to live in their home and community.



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Services for Children with Complex Behavioral Health Needs

The North Carolina Department of Health and Human Services (NC DHHS) has made policy changes in order to better serve children with complex behavioral health needs. The agency took this action in response to a complaint Disability Rights NC filed alleging that NC DHHS was not meeting its obligations to these children.

For this fact sheet, **children with complex needs** are those who meet these four criteria:

1. They have been diagnosed with an intellectual and/or developmental disability (I/DD) and a mental illness;
2. They are at risk of not being able to enter or remain in a community setting (that is, they are institutionalized or are at risk of being institutionalized);
3. They have Medicaid; and
4. They are 5 years old to 20 years old (eligibility ends on one's 21st birthday).

These children are covered by a provision in federal Medicaid law called Early and Periodic Screening, Diagnostic and Treatment (EPSDT). This provision requires NC DHHS to provide the children with "necessary health care, diagnostic services, treatment and other measures in order to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services."

Seven LME/MCOs (local management entities/managed care organizations) administer these services in North Carolina. Go to www.ncdhhs.gov/providers/lme-mco-directory to find out which LME/MCO covers your county and to get contact information.

Disability Rights NC reached a settlement agreement with NC DHHS in response to its complaint. Under the agreement, NC DHHS promises to provide the following services for children who meet the four criteria listed above.

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Champions for Equality and Justice

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT): A Medicaid Rule that Guarantees Services for Children

EPSDT is part of the federal Medicaid Act. The Act entitles **children under age 21 who have Medicaid** to all services that are medically necessary to make or keep them physically and mentally healthy. State Medicaid programs must cover any service that is medically necessary to correct or ameliorate a child's physical or mental condition.

A service is **medically necessary** when it corrects or ameliorates a condition. A service or treatment **ameliorates** a condition if it does one or more of the following:

- Improves or maintains the recipient's health in the best condition possible;
- Compensates for a health problem;
- Prevents a health problem from getting worse; or
- Prevents the development of additional health problems.

The State must cover medically necessary services even if those services are not otherwise covered under the State Medicaid Plan.

EPSDT Services

EPSDT includes both short-term and long-term services. It also includes durable medical equipment, prosthetics, wheelchairs, oxygen equipment, communication aides, and other equipment—as long as they are medically necessary.

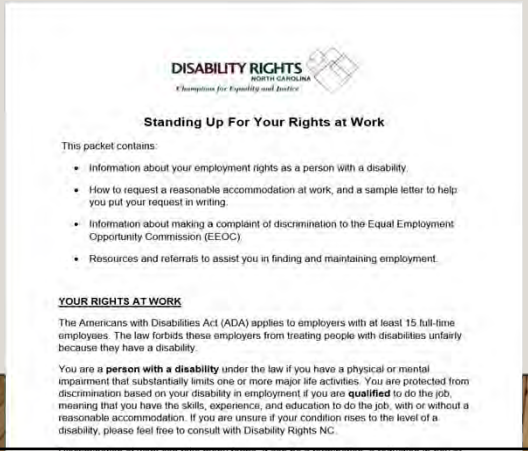
Under the federal Medicaid law, there are mandatory services, which states must provide to Medicaid recipients, and optional services, which states may provide. EPSDT requires that the State Medicaid program provide **all mandatory and optional services** to children who have Medicaid, if those services are medically necessary.

What happens during a Facility Intake

- Patients calling from Central Regional, Cherry Hospital, Broughton Hospital, and Holly Hill will automatically be sent to our intake specialist to triage.
- These are state operated hospitals in which we have advocates that regularly monitor these facilities.
- The patients will be asked if they have contacted the internal patient advocate at the hospital with their concerns.
- If there is a concern regarding the care they are receiving from the facility, and they have contacted the internal advocate, the monitor of the facility will be notified of their concerns. They may also request for a visit from our monitors, in which the monitor will be notified.

- If a caller is contacting DRNC from a facility in which we do not monitor, the call will be processed as a regular intake call.
- Abuse/neglect/exploitation complaints can be made by a patient, guardian, non-guardian or an anonymous caller.
- All abuse/neglect/exploitation calls are immediately processed and sent to our Investigations and Monitoring Team Lead to review.
- If a caller is making an allegation regarding their Representative Payee, that call is sent to the Director of Investigations and Monitoring.

Target 3. Employment of people with disabilities in competitive and integrated jobs.



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Standing Up For Your Rights at Work

This packet contains:

- Information about your employment rights as a person with a disability.
- How to request a reasonable accommodation at work, and a sample letter to help you put your request in writing.
- Information about making a complaint of discrimination to the Equal Employment Opportunity Commission (EEOC).
- Resources and referrals to assist you in finding and maintaining employment.

YOUR RIGHTS AT WORK

The Americans with Disabilities Act (ADA) applies to employers with at least 15 full-time employees. The law forbids these employers from treating people with disabilities unfairly because they have a disability.

You are a **person with a disability** under the law if you have a physical or mental impairment that substantially limits one or more major life activities. You are protected from discrimination based on your disability in employment if you are **qualified** to do the job, meaning that you have the skills, experience, and education to do the job, with or without a reasonable accommodation. If you are unsure if your condition rises to the level of a disability, please feel free to consult with Disability Rights NC.

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Working with Vocational Rehabilitation (VR)

This packet contains information about:

1. the North Carolina VR program;
2. how to request VR goods and services;
3. available VR goods and services; and
4. your VR rights.

To help you make the most of your VR services, this packet also includes:

5. tips for being a good advocate for yourself in the VR process;
6. information about appealing VR decisions you do not agree with and sample letters you may use in making your appeal;
7. a checklist to help you stay on track with the VR process;
8. a chart of all the available VR goods and services; and
9. contact information for each VR office.

The North Carolina Vocational Rehabilitation (VR) Program

The VR program provides goods and services to help people with disabilities get jobs and support themselves. Depending on your interests, VR can help you prepare for work, get a job, keep your job, get your job back, earn higher pay or get promotions in your current job. Any job you get with the help of VR must pay you at least a minimum wage and be in a workplace that includes coworkers without disabilities.

Target 10. Promote Self Determination.

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Alternatives to Guardianship

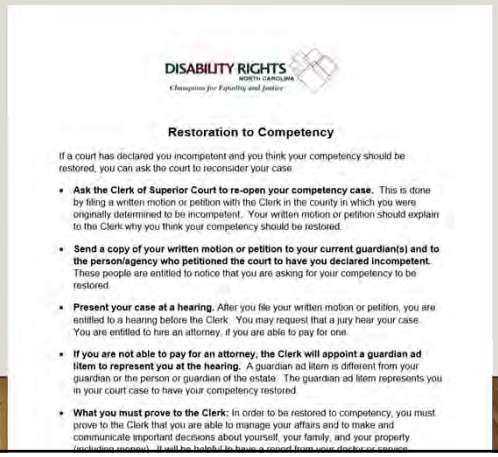
Guardianship is an extreme form of intervention in another person's life because control over personal and/or financial decisions is transferred to someone else for an indefinite, often permanent, period of time. Once established, it can be difficult to revoke. Therefore guardianship should be used only as a last resort. Less restrictive alternatives that can maintain the person safely in the community should be pursued.

The following are common alternatives to guardianship that should be explored before determining that a guardianship or even a limited guardianship is necessary.

Family and Community Supports

Whether or not someone needs guardianship may depend on the supports the person has in the community and at home. All of us routinely rely on the expertise of others. For example, we rely on car mechanics as well as physicians to help us make and implement decisions. A person with a cognitive disability who does not have the capacity to manage all of the details of their life may not need a guardian if they can and do rely on others who are available to support them. For example, someone with a developmental disability who cannot do the math to balance their budget or bank account may not need a financial guardian if they know they need help in this area, and there is an available and appropriate person to whom the person is willing to turn for assistance.

Home health agencies exist to assist with activities of daily living (i.e. bathing, cooking, and cleaning) and can support someone in the community who retains their ability to make decisions about their care. Medicaid has services called skilled nursing care and home health services that may be available. The services can be purchased from a home health



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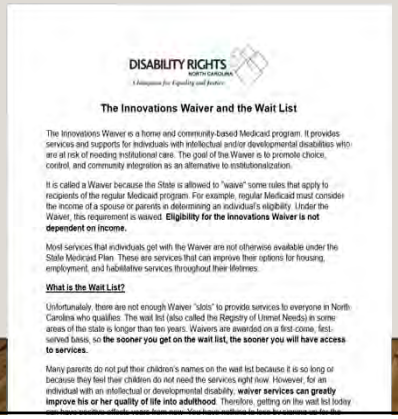
Restoration to Competency

If a court has declared you incompetent and you think your competency should be restored, you can ask the court to reconsider your case.

- **Ask the Clerk of Superior Court to re-open your competency case.** This is done by filing a written motion or petition with the Clerk in the county in which you were originally determined to be incompetent. Your written motion or petition should explain to the Clerk why you think your competency should be restored.
- **Send a copy of your written motion or petition to your current guardian(s) and to the person/agency who petitioned the court to have you declared incompetent.** These people are entitled to notice that you are asking for your competency to be restored.
- **Present your case at a hearing.** After you file your written motion or petition, you are entitled to a hearing before the Clerk. You may request that a jury hear your case. You are entitled to hire an attorney, if you are able to pay for one.
- **If you are not able to pay for an attorney, the Clerk will appoint a guardian ad litem to represent you at the hearing.** A guardian ad litem is different from your guardian or the person or guardian of the estate. The guardian ad litem represents you in your court case to have your competency restored.
- **What you must prove to the Clerk:** In order to be restored to competency, you must prove to the Clerk that you are able to manage your affairs and to make and communicate important decisions about yourself, your family, and your property (including money). It will be helpful to have a report from your doctor or psych

HOME TEAM (MEDICAID), HOUSING, COMMUNITY ACCESS

Target 6. Reduce unnecessary institutionalization of individuals with disabilities and advance home and community based healthcare services and supports.



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The Innovations Waiver and the Wait List

The Innovations Waiver is a home and community-based Medicaid program. It provides services and supports for individuals with intellectual and/or developmental disabilities who are at risk of needing institutional care. The goal of the Waiver is to promote choice, control, and community integration as an alternative to institutionalization.

It is called a Waiver because the State is allowed to "waive" some rules that apply to recipients of the regular Medicaid program. For example, regular Medicaid must consider the income of a spouse or parents in determining an individual's eligibility. Under the Waiver, this requirement is waived. **Eligibility for the Innovations Waiver is not dependent on income.**

Most services that individuals get with the Waiver are not otherwise available under the State Medicaid Plan. These are services that can improve their options for housing, employment, and habilitative services throughout their lifetimes.

What is the Wait List?

Unfortunately, there are not enough Waiver "slots" to provide services to everyone in North Carolina who qualifies. The wait list (also called the Registry of Unmet Needs) in some areas of the state is longer than two years. Waivers are awarded on a first-come, first-served basis, so **the sooner you get on the wait list, the sooner you will have access to services.**

Many parents do not put their children's names on the wait list because it is so long or because they feel their children do not need the services right now. However, for an individual with an intellectual or developmental disability, **waiver services can greatly improve his or her quality of life into adulthood**. Therefore, getting on the wait list today

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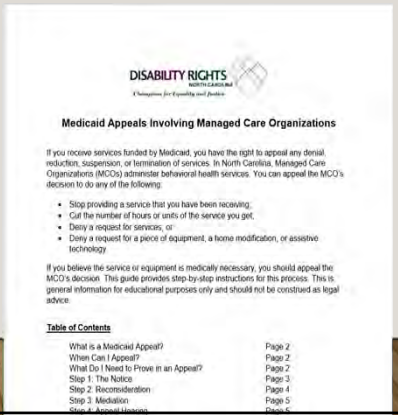
Eligibility Requirements for the Innovations Waiver

What is the Innovations Waiver?

The North Carolina Innovations Waiver ("Waiver")[1] is a home and community-based Medicaid program that provides services and supports for individuals with intellectual and/or developmental disabilities that are at risk of institutional care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IDD). The Waiver replaced the CAP-MR/DD program. The goal is to provide an array of community-based services and supports to promote choice, control, and community integration as an alternative to institutionalization. Many of these services are not otherwise available under the State Medicaid Plan. The Division of Medical Assistance (DMA) is the NC Medicaid agency that is responsible for operating the Medicaid program in North Carolina. It operates the Waiver by contracting with Local Management Entity/Managed Care Organizations (LME/MCOs) to manage the delivery of services, although DMA is still responsible for oversight of the program. Additional information regarding the Waiver can be found at http://www.ncdhhs.gov/dma/lme/innovations.html and in DMA Clinical Coverage Policy 8P-2.

Unfortunately, there are only a limited number of Waiver "slots," so that although an individual may be eligible for the Waiver, there may not be a slot available for them to be able to immediately receive services. The wait list for the program is known as the Registry of Unmet Needs ("Registry") that is kept by the LME/MCO. Because of the high demand for these services, the wait list is extremely long and it could take many years before a slot becomes available. There is no entitlement to services under the Waiver.

[1] The program is called a "Waiver" because North Carolina is permitted to "waive" certain Medicaid



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Champions for Equality and Justice

Medicaid Appeals Involving Managed Care Organizations

If you receive services funded by Medicaid, you have the right to appeal any denial, reduction, suspension, or termination of services. In North Carolina, Managed Care Organizations (MCOs) administer behavioral health services. You can appeal the MCO's decision to do any of the following:

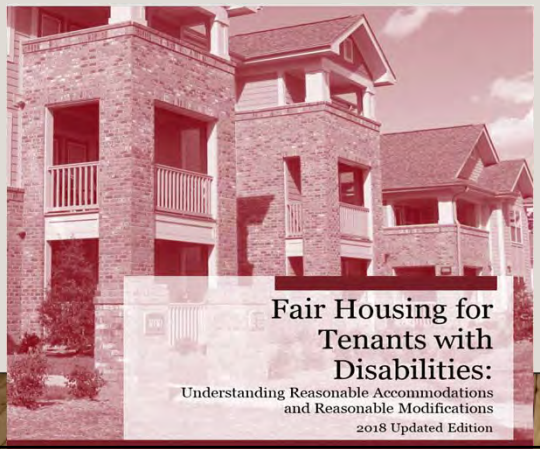
- Stop providing a service that you have been receiving;
- Cut the number of hours or units of the service you get;
- Deny a request for services; or
- Deny a request for a piece of equipment, a home modification, or assistive technology.

If you believe the service or equipment is medically necessary, you should appeal the MCO's decision. This guide provides step-by-step instructions for this process. This is general information for educational purposes only and should not be construed as legal advice.

Table of Contents

What is a Medicaid Appeal?	Page 2
When Can I Appeal?	Page 2
What Do I Need to Prove in an Appeal?	Page 2
Step 1: The Notice	Page 3
Step 2: Reconsideration	Page 4
Step 3: Mediation	Page 5
Step 4: Appeal Hearing	Page 6

Target 7. Increase accessible and affordable housing.



DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

Animals and the Fair Housing Act

Under the Fair Housing Act, tenants and homeowners are allowed to have service animals and emotional support/comfort/assistance animals in their homes as well as in common areas and places of public accommodation in a housing complex. This right extends to prospective tenants or homeowners and to guests of tenants or homeowners.

The Fair Housing Act

The Fair Housing Act (FHA) prohibits discrimination in housing on the basis of race, color, religion, sex, national origin, familial status, and disability. The FHA says discrimination includes "a refusal to make reasonable accommodations in rules, policies, practices, or services, when such accommodations may be necessary to afford such person [with a disability] equal opportunity to use and enjoy a dwelling."

A **reasonable accommodation** is "a change, exception, or adjustment to a rule, policy, practice, or service that may be necessary for a person with a disability to have an equal opportunity to use and enjoy a dwelling, including public and common use spaces."

Courts have found that an exception to a "No Pets" policy is reasonable accommodation when the person with the disability can show a link between his/her disability and the need for the animal.

Who is Protected under the Fair Housing Act?

The FHA protects persons with disabilities from housing discrimination. It protects the tenant or homeowner with a disability as well as people with disabilities who are associated with a tenant or homeowner, such as guests.

Target 4. People with disabilities have access to their community.

DISABILITY RIGHTS NORTH CAROLINA

The ADA and Public Places: Access, Accessibility, and Advocacy

What Is the Americans with Disabilities Act (ADA)?

The Americans with Disabilities Act (ADA) is a federal civil rights law protecting people from discrimination based on disability. It requires public accommodations, employers, transportation providers, state and local governments, and telecommunications to be accessible to people with disabilities. Title Three of the ADA applies specifically to places of public accommodation. This publication provides a general overview of your rights under Title Three of the ADA.

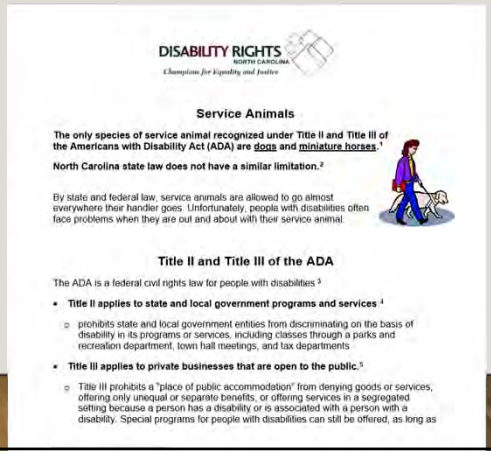
Note: The ADA uses Roman numerals to identify its different titles—e.g., Title III. We are spelling out the numbers to improve accessibility of this document.

What Is Accessibility?

Accessibility means that people with disabilities are able to access the same buildings, programs, goods, and services as people without disabilities. Accessibility is not limited to physical access; it also includes communication access.

What Is a Place of Public Accommodation?

Places of public accommodation are private businesses or organizations that provide goods, services, facilities, privileges, advantages, or accommodations to the public. Examples include hotels, restaurants, movie theaters, stadiums, shopping centers, grocery stores, banks, hospitals, lawyers' offices, museums, zoos, private schools, homeless shelters, and golf courses. Title Three applies to all public accommodations, regardless of how many employees they have.



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Service Animals

The only species of service animal recognized under Title II and Title III of the Americans with Disability Act (ADA) are dogs and miniature horses.[1]

North Carolina state law does not have a similar limitation.[2]

By state and federal law, service animals are allowed to go almost everywhere their handler goes. Unfortunately, people with disabilities often face problems when they are out and about with their service animal.

Title II and Title III of the ADA

The ADA is a federal civil rights law for people with disabilities [3]

- **Title II applies to state and local government programs and services** [4]
  - prohibits state and local government entities from discriminating on the basis of disability in its programs or services, including classes through a parks and recreation department, town hall meetings, and tax departments
- **Title III applies to private businesses that are open to the public.**[5]
  - Title III prohibits a "place of public accommodation" from denying goods or services, offering only unequal or separate benefits, or offering services in a segregated setting because a person has a disability or is associated with a person with a disability. Special programs for people with disabilities can still be offered, as long as

DISABILITY RIGHTS NORTH CAROLINA
Champions for Equality and Justice

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To achieve full equality and justice for people with disabilities, we need to accomplish many different goals. But we do not have the resources to tackle all of those goals at one time.

Through public input and our work with clients, we identify problems that are widespread and threaten the independence of people with disabilities. Then we develop Targets to address those problems.

Why Do We Need Targets?

Disability Rights NC is the federally mandated protection and advocacy (P&A) system in North Carolina. Most of our funding comes from the federal government, which requires Targets. Our Targets guide the work of our legal teams and provide the structure within which we spend our limited resources.

What Other Work Does Disability Rights NC Do?

We provide self-advocacy tools to help people with disabilities learn about and enforce their rights. We conduct investigations and monitoring of facilities where people with disabilities live or receive services. We conduct reviews of representative payees' records to protect people with disabilities who receive Social Security benefits. We engage in public policy advocacy.

Keep students with disabilities in school.

Students with disabilities are susceptible to being excluded from school when they exhibit challenging behaviors, even when those behaviors are related to their disabilities. Students with disabilities are excluded from school more often than students without disabilities through suspensions, homebound placements, modified day schedules, and other exclusionary practices.

During the 2015-16 school year, more than 22% of the long-term suspensions and more than 24% of the short-term suspensions were given to students with disabilities, yet students with disabilities are less than 13% of the total student population. These exclusions often result in months and sometimes years of lost instructional time for students with disabilities. In 2015-16, the average length of a long-term suspension was 76 school days—that's more than 40% of the school year.

Students with IEPs are, in effect, suspended when the IEP team changes their placement from the school setting to homebound or to a modified day schedule. With homebound placement, the student is not allowed to come to school and usually receives two to four hours of instruction per week. With a modified day placement, the student is allowed to come to school for only part of the school day. We receive many calls from parents whose children have been on homebound or modified day schedules for most or all of a given school year.

Target Populations:

- Students with disabilities who have received a lengthy homebound placement or modified school schedule who can be served in a less restrictive setting if the school provides an appropriate placement, supports and services.
- Students with disabilities who have received long-term suspensions or multiple short-term suspensions without the benefit of the disciplinary safeguards in the Individuals with Disabilities Education Act..
- Students with disabilities who are, in effect, suspended because the principal has asked their parents to pick them up from school for more than 10 days.

Funding: PAIDD, PAIR, PAIMI, PAAT

Go to page 9 for an explanation of the funding acronyms.

Ensure that students with disabilities attend school free from abuse, including abusive interventions.

Many students with disabilities are subject to abuse at school, including physical and emotional abuse by school staff and the use of restrictive interventions, such as seclusion and restraint. Students with disabilities are particularly vulnerable to mistreatment. One study concluded that one in three children with an identified disability receiving special education services is a victim of neglect, physical abuse, or sexual abuse.

This problem is compounded by reporting and exclusion issues. Many children with disabilities are unable to report abuse because of communication issues related to their disability. In addition, they may attend school in segregated settings, including separate schools and self-contained classrooms, that allow the abuse to go undetected and unreported.

This year, Disability Rights NC received a new grant from the Governor's Crime Commission. This grant enables us to monitor in self-contained classrooms and separate schools designated for children with behavioral or intellectual disabilities. We will look for signs of abuse, including the inappropriate use of seclusion and restraint, and we will investigate allegations of abuse. We will also educate school staff about how abuse happens and best practices for working with children with disabilities.

Students with disabilities should attend school in a safe environment, free from traumatic experiences from abuse and abusive interventions. The work of this Target will focus on systemic changes to school-system practices in order to prevent abuse and abusive interventions from occurring or remaining undetected.

Target Populations:

- Students with disabilities with communication challenges.
- Students with disabilities in separate classrooms and separate schools.
- Students with disabilities with significant behavior challenges.

Funding: PAIDD, PAIR, PAIMI, PAAT, GCC

Address North Carolina over-reliance on psychiatric residential treatment facilities (PRTFs).

Since 2010, the number of PRTF beds in the state has increased by 119% to 1,081. This does not include the children and adolescents who North Carolina sends to PRTFs in other states. Rather than increasing these institutional beds, North Carolina should be ensuring that children get the services they need in their communities. Medicaid Transformation and the State's development of Tailored Plans must include community services that will dramatically reduce reliance on PRTFs.

A 2013 report to Congress detailed a five-year demonstration project to determine whether children and adolescents could be better served in the community through Medicaid Waiver services than in PRTFs. That study found:

1) "Children and youth generally maintained or improved their functional status when receiving services in the community"; and
2) "Waiver services cost about a third (32 percent) of comparable services provided in PRTFs."

In other words, the children in the demonstration project fared better or the same when receiving the right services in the community, and those services saved 68 percent compared to the cost of PRTFs.

Many children and adolescents in NC's PRTFs cycle in and out of psychiatric hospitals, PRTFs, and the community. Through our monitoring work, we have seen children who have cycled through numerous PRTFs throughout the state, often times far away from their families and other natural supports for weeks, months, and even more than a year. We know through our monitoring efforts and regulatory surveys that some children are abused and neglected in these settings. Some PRTFs fail to recognize and address children's trauma histories, thereby perpetuating the underlying trauma. PRTFs are potentially setting up generations of North Carolina's children and adolescents for a lifetime of misdiagnoses and mistreatment.

This Target proposes to reduce NC's reliance on these institutional settings by developing and making available information to policy makers and the public that will demonstrate the need to shift resources back to the community for our youth.

Target Populations: Students with disabilities who are under the age of 18 and residing in a PRTF.

Funding: PAIDD, PAIMI

Advocate for the employment of people with disabilities in competitive and integrated jobs.

People with disabilities continue to face barriers to finding work and staying on the job. Some choose not to work more hours or earn higher wages for fear of losing benefits. Sheltered, subminimum wage workers are denied full inclusion in our workforce.

Work is the foundation for economic stability. Our clients must have information about work incentives programs and access to competitive employment, free from discrimination.

Target Populations:

- People with disabilities who receive vocational training in segregated settings.
- People with disabilities facing employment discrimination or other barriers to employment, including lack of reasonable accommodations or lack of transition services.
- People with disabilities without adequate information about work incentives and other resources to help them find and maintain employment.

Funding: PAIDD, PAIR, PATBI, PABSS, PAAT, PAIMI

Enforce the right of people with disabilities to have equal access to their communities.

People with disabilities are regularly denied the full and equal enjoyment of the services offered by businesses, local municipalities, and the State.

Target Populations:

- People with disabilities who have been denied equal access to public places, programs, or services.
- People with disabilities who have been denied accommodations/modifications by colleges and universities.

Funding:

PAIDD, PAIR, PATBI, PAAT

Reduce unnecessary institutionalization of individuals with disabilities and advance home and community-based healthcare services and support

The current health and human services system is biased toward institutionalization over home and community-based services. Often, people with disabilities who could successfully live in the community with sufficient services and supports are stuck in institutional settings. Others currently living in the community are put at risk of unnecessary institutionalization and segregation due to cost-cutting measures and a flawed implementation of the service delivery system.

This system violates the rights of individuals with disabilities to receive services in the least restrictive environment under the Americans with Disabilities Act and the *Olmstead* decision. Additionally, the State fails to comply with federal Medicaid law regarding the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of Title XIX of the Social Security Act (Medicaid Act).

We will take a holistic approach to address these issues in order to reduce institutionalization, promote community integration, and promote access to medically necessary services. We will work to ensure that adults and children with disabilities can live where they want and have the services they need to have fulfilled and integrated lives.

Target Populations:

- Adults and children with disabilities in institutions who could be more appropriately served in home and community-based settings.
- Adults and children with disabilities in integrated settings whose rights to community-based services have been denied.
- Adults and children with disabilities who face an increased risk of institutionalization because of inadequate home and community-based service systems.
- People without adequate information to enforce their rights to transition into the community and receive needed health care services.

Funding: PAIDD, PAIMI, PATBI, PAIR, PAAT

Increase access to accessible, affordable housing for people with disabilities in the communities of their choice.

Disability Rights NC receives numerous calls from individuals who are being discriminated against in housing due to disability. They are living in homes that are not accessible for their needs, or they simply cannot find accessible, affordable housing so they can live independently in the community of their choice.

We are committed to increasing access to housing so people with disabilities can live independently in the community and have full use and enjoyment of their homes. We will utilize Protection and Advocacy tools—including targeted individual representation, education and training, and systemic advocacy—to increase access to and funding for safe, affordable, accessible housing.

Target Populations:

- People with disabilities who have been denied equal access to fair housing.
- People with disabilities who want to live in safe and accessible housing in communities of their choice.

Funding: PAAT, PAIMI, PAIDD, PATBI, PAIR

Promote the right of self-determination.

Self-determination is the fundamental right to make decisions and shape one's own life. Guardianship permits an individual, a corporation, or the government to stand in the shoes of a person with a disability and make decisions on their behalf. Guardianship almost always results in the loss of some or all decision-making authority belonging to a person with a disability. Advocating for the right of people with disabilities to self-determination is fundamental to our purpose as a P&A.

Target Populations:

- People with disabilities who would like to restore their competence.
- People with disabilities who have public or corporate guardians and would like to live in the community.

Funding: PAIDD, PAIMI, PAIR, PATBI, PABSS

Monitor jail deaths, advocate for improved treatment, and advocate for improved jail rules, including mandatory suicide prevention programs.

Jails are neither designed nor funded to provide mental health treatment, yet with the erosion of public mental health services, they have increasingly become de facto mental health facilities. Recently, two people died in NC jails after they were placed in single cells to prevent self-injury. One suffocated himself with toilet paper, using a blanket to shield his actions from a camera (December 30, 2017). The other hung himself in the "watch" cell when officers failed to conduct the required 15-minute observation (January 14, 2018). To date in 2018, five people have died by suicide in North Carolina jails. Advocacy is needed to ensure jail administrators appropriately respond to an inmate in a mental health crisis.

The NC Department of Health and Human Services is currently considering updates to the North Carolina Jail Regulations. Among the proposals are mental health and intellectual/developmental disabilities (I/DD) screening and treatment and mandatory suicide prevention programs. These updates are critical to improving the treatment of people with disabilities incarcerated in our local jails. Advocacy will be needed to press the proposals through the rule-making process.

There are few organizations monitoring conditions in NC jails. Disability Rights NC can have a meaningful impact of the quality of care for people with disabilities.

Target Population: People with disabilities confined in North Carolina jails.

Funding: PAIMI, PAIDD, PAIR

Ensure appropriate treatment for people with mental health disabilities in NC prisons and enforce the right of prisoners with disabilities to accommodations required by the ADA.

There are more North Carolinians with severe mental illness in our prisons and jails than in our psychiatric hospitals. Prisoners with I/DD often are not identified or accommodated, placing them in situations where they are vulnerable to abuse and neglect. Currently there is no routine screening for traumatic brain injury (TBI).

Through Protection and Advocacy system monitoring and investigation of abuse and neglect, and by collaborating with other advocacy groups, Disability Rights NC

can impact how people with mental health disabilities are identified and treated in our prisons and increase the chances that people can be successful upon release.

Prisoners with disabilities also face discrimination in access to programs and services and suffer hardships additional to the loss of freedom. Through Disability Rights NC's on-going advocacy in the prison system, we have learned that the prison-ADA system fails to identify and accommodate prisoners with disabilities. Our goal is to remedy the ADA system in NC prisons so that inmates with disabilities are no longer discriminated against and are able to access programs and services while in prison and as part of their preparation for successful reentry upon release.

Target Populations:

- People with mental health disabilities in prison who are not identified and who are not receiving appropriate treatment.
- People with disabilities in prison who are not receiving accommodations and who are denied equal access to prison programs and services.

Funding: PAIMI, PAIDD, PATBI, PAIR, PAAT

Funding Acronyms

The acronyms at the end of each Target show you what grants fund that work. The Protection and Advocacy grants come from the federal government.

PAAT — Protection and Advocacy for Assistive Technology
PABSS — Protection and Advocacy for Beneficiaries of Social Security
PABRP — Protection and Advocacy for Beneficiaries with Representative Payees
PAIDD — Protection and Advocacy for Individuals with Developmental Disabilities
PAIMI — Protection and Advocacy for Individuals with Mental Illness
PAIR — Protection and Advocacy for Individual Rights
PATBI — Protection and Advocacy for Traumatic Brain Injury
PAVA — Protection and Advocacy for Voting Access
IOLTA — North Carolina State Bar Plan for Interest on Lawyers' Trust Accounts
GCC — Governor's Crime Commission

Keep people safe in facilities through monitoring efforts.

Consistent with our federal mandate, Disability Rights NC monitors facilities where people with disabilities live or receive services in order to prevent, detect, and address instances of abuse, neglect, or exploitation. We also want to ensure appropriate services are provided, that the environment is safe for the individuals, and that individuals are provided opportunities to participate in activities and work that is important to them. Finally, we want to identify people who could live in the community if they had the proper supports. In short, we monitor to ensure legal compliance with respect to the rights and safety of residents.

Target Population: People with disabilities living in facilities whose rights must be identified and protected.

Funding: PAIDD, PAIMI, PAIR, PATBI

Keep people safe in facilities by investigating deaths and allegations of abuse and neglect.

The protection and advocacy system was created in the 1970s as a result of systemic, horrific abuse and neglect of people with intellectual and developmental disabilities in a New York state-operated facility called Willowbrook.

People with disabilities who live in facilities are particularly vulnerable to abuse or neglect. Cuts to community-based services results in more institutionalization of people with disabilities at a time when providers are paid less for those services. This impacts both the quality and level of care, increasing the risks of abuse and neglect.

Our monitoring efforts can and do reveal the need for investigations, but we also initiate investigations based upon complaints we receive. This means investigations are more reactionary, providing us less ability to predict or control the work. When a compelling cases arises, we must adjust and modify other investigations and other team work so that we can take it on, even when we are at full capacity.

Target Population: People with disabilities living in facilities whose rights must be identified and protected to ensure they are safe and free from abuse, neglect or exploitation.

Funding: PAIDD, PAIMI, PAIR, PATBI

Monitor and investigate how representative payees administer Social Security funds for beneficiaries.

A representative payee is a person who acts as the receiver of Social Security Disability or Supplemental Security Income for a person who is not fully capable of managing their own benefits. Unfortunately, multiple investigations have uncovered representative payees who have stolen or misused funds and exploited, neglected, and even abused the people with disabilities they were supposed to be helping.

In 2018, the federal government authorized the nation's Protection and Advocacy system to monitor and investigate how representative payees administer Social Security funds. Under the new Protection and Advocacy for Beneficiaries with Representative Payees grant program, Disability Rights NC will conduct periodic onsite reviews of representative payees' financial records, as ordered by the Social Security Administration. We will also conduct reviews at our discretion. If we find that a representative payee is not fulfilling his duties, we will notify the Social Security Administration and create a corrective action plan.

Target Population: People with disabilities who receive Social Security benefits and have representative payees.

Funding: PABRP

What It Means to be a P&A

Congress created the nation's Protection and Advocacy (P&A) system in 1975 to stop the abuse and neglect of people with disabilities. The government mandates that every state have a P&A agency. We are the P&A for North Carolina. As a P&A, our responsibilities include the following:

- Ensuring that people with disabilities live in safe and humane conditions
- Informing individuals about their legal rights and how to enforce them
- Ensuring that people with disabilities are not unnecessarily institutionalized
- Enforcing the rights of all North Carolinians with disabilities under federal and state law

Our work covers the entire range of disability, including physical impairments, visual and hearing impairments, intellectual and developmental disabilities, mental illness, and traumatic brain injury. More than 4,000 people call our office every year seeking assistance.

Public Policy and Legislative Advocacy

In addition to our legal advocacy, monitoring, and investigations work, we pursue system change through policy advocacy, including lobbying. We cannot and do not use federal funds to conduct lobbying activities.

Legislative and regulatory advocacy is a critical piece of our work. Laws and regulations are often the underlying cause of the problems people with disabilities face. We also focus on public benefit programs because they are often the only way people with disabilities can get the services they need.

Disability Rights North Carolina is a federally mandated protection and advocacy system with funding from the U.S. Department of Health and Human Services, the U.S. Department of Education, and the Social Security Administration.

We are an independent 501(c)(3) nonprofit organization. Our team of attorneys, advocates, paralegals, and support staff provide advocacy and legal services at no charge for people with disabilities across North Carolina.

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Esta información está disponible en Español.

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

The R.I.C.H. Approach
(Respect, Individuality, Connection & Hope)

Contents

- The R.I.C.H. Approach Outline, Objective and Agenda

Tonier Cain

R.I.C.H. APPROACH OUTLINE

Program Objectives

After This Session, Participants Will Be Able to:

1. Identify The Primary Components of Trauma-Informed Practice
2. Utilized The R.I.C.H. Approach to Strengthen Partnerships with Clients
3. Apply Two Cases to The R.I.C.H. Approach
4. Demonstrate Their Ability to Use The R.I.C.H. Approach on A Case

Program Agenda

1. Setting the Stage

2. Reminder: What is Trauma-Informed Practice?

3. A Trauma-Informed Practice for Strengthening Relationships and Measuring Progress

4. Group Work (R.I.C.H. Approach)

I. Trauma-Informed Practice

A. Trauma Defined

B. Trauma Revealed

C. R.I.C.H. Model

I. Respect -

II. Information -

III. Connection -

IV. Hope -

II. R.I.C.H. Model

A. Strengthen Partnerships

B. Develop Connections

C. Provide (Appropriate Trauma-Informed) Services

D. Improve Quality

III. R.I.C.H. Scenarios

IV. Applying the R.I.C.H. Model

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

Trauma-Informed Legal Advocacy

Contents

- PowerPoint Presentation Handout
- Birth Parents with Trauma Histories
- Helping Traumatized Children: Tips for Judges
- Letter to Judges re NCTSN Bench Card AND NCTSN Bench Card for Judges
- Secondary Traumatic Stress: A Fact Sheet for Child-Serving Professionals
- Self-Care Inventory
- Social Wellness Checklist
- What is Child Traumatic Stress: includes what is a traumatic event

WHAT IS "TRAUMA-INFORMED LEGAL ADVOCACY"?

- Trauma-Informed Legal Advocacy:
  - System-wide approach (i.e., attorneys, caseworkers, judges) in "understanding the causes and effects of traumatic experiences and incorporate practices that support recovery"
  - Recognize impact of trauma
  - Respond in trauma-informed way
  - Avoid legal practices that may re-traumatize youth and families
  - Promote recovery and resilience

COMPONENTS OF TRAUMA-INFORMED LEGAL ADVOCACY

Impact of Trauma Exposure on Child Development (impact on brain and behavior which can be treated, promotion of resilience, need for screening and trauma-informed assessment)
Impact of Trauma Exposure on caregiver* (discussion of intergenerational trauma, impact of trauma exposure on caregivering practices, impact of trauma exposure on caregiveral reactions to court proceedings)
Impact of Trauma on the Attorney – Client Relationship (physical and psychological safety, communication, recognizing and responding to triggers, importance of staying connected with family, resiliency)
Screening and Assessment (Screening, trauma-informed assessment, and neuropsychological evaluations)
Effective Treatments for Traumatic Stress (evidence-based interventions, core elements of trauma-informed treatment)
Placement Decisions, Transitions, and Visitation (impact of placement disruption, placement decisions, planful transitions, psychologically safe visitations)
Secondary Traumatic Stress and Attorneys (STS definition, risk factors, prevention, importance of self-care)
Importance of Collaboration (collaboration and coordination among service providers)

~National Child Traumatic Stress Network, Justice Consortium Attorney Workgroup Subcommittee (2017)

THE IMPORTANCE OF UNDERSTANDING THE IMPACT OF TRAUMA

- Why is it important for those in the legal system to understand the impact of trauma?
  - Provides opportunity to refer the client to appropriate treatment – contributes to rehabilitation
  - Provides opportunity to detect triggering and maladaptive environments and place the client in a safe, stable nurturing environment → Safety, predictability and responsiveness in the client's environment can help buffer future difficulties

(Buffington et al., 2010; Mercy & Saul, 2003)

WHAT SHOULD LAWYERS KNOW ABOUT TRAUMA?

I. What is trauma/traumatic stress?
II. What can cause trauma?
III. What are potential consequences of trauma?
IV. What are signs of trauma?
V. What should a lawyer consider in representing a client who has experienced trauma?
VI. What is the impact of trauma on the attorney-client relationship?

I. WHAT IS TRAUMA?

- Exposure to events that involve threats of injury, death, or danger where intense terror, anxiety, and helplessness is experienced
- Can occur via direct experience, witnessing the event, or even hearing about the event
- Reactions vary with age, but even very young clients can experience intense reactions
- Possible intense physical effects → Rapid heartbeat and breathing, shaking, dizziness, and/or loss of bladder or bowel control

(Gerrity, 2013; NCTSN, 2010)

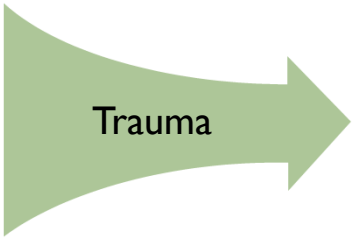
TYPES OF TRAUMA

- Acute – Single event; lasts for short time
- Neglect – Failure to provide for client's basic needs
  - Considered a trauma for child or client completely dependent on adults
  - Can increase risk of additional traumatic events
- Complex Trauma – Specific type of chronic trauma
  - Multiple traumatic events
  - Begins at a young age
  - Caused by adults who were supposed to care for and protect client

(NCTSN, 2010)

I. POSTTRAUMATIC STRESS DIAGNOSIS

- Although many clients demonstrate symptoms of traumatic stress, some clients exposed to violence may develop Post-Traumatic Stress Disorder (PTSD)



PTSD is diagnosed when **four categories of symptoms** are present:
-Re-experiencing/Intrusion
-Avoidance/Numbing
-Negative Alterations in Thoughts/Mood
-Hyperarousal/Heightened Reactivity

II. TYPES OF TRAUMATIC EVENTS

- Trauma may be embedded in daily life, may be chronic, or may be an acute event:
  - Abuse and Maltreatment
  - Neglect, or severe deprivation
  - Intimate Partner Violence/Domestic Violence
  - Community Violence
  - Sexual Assault
  - Medical Trauma
  - Traumatic Loss and Bereavement
  - Accident/Fires
  - Natural Disasters
  - War/Terrorism/Political Violence

(Angela M. Tunno, Ph.D., M.S.; Gerrity, 2013)

II. EXAMPLES OF OTHER TRAUMATIC EVENTS
[BASED ON THE ADVERSE CHILDHOOD EXPERIENCES STUDY (ACES)]

- Involvement in the immigration, child welfare, or juvenile justice system
- Separation from families through death, placement into the foster care system, or having an incarcerated parent
- Poverty
- Bullying

(Eliza Hirst and Cathy Krebs, American Bar Association)

III. POTENTIAL CONSEQUENCES OF TRAUMA

CENTER FOR CHILD & FAMILY HEALTH

III. BRAIN DEVELOPMENT AND FUNCTIONING

Trauma can affect the parts of the brain that:

- Regulate attention and awareness
- Make decisions about the best response to a situation
- Initiate conscious voluntary behavior
- Regulate emotions
- Inhibit or correct dysfunctional reactions

(Melanie Greenberg, Ph.D., Psychology Today, September 2018)

III. BRAIN DEVELOPMENT AND FUNCTIONING

These brain dysfunctions can cause:

- Hyperarousal
- Intrusive thoughts
- Hypervigilance
- Startle responses
- Increased wakefulness and sleep disturbances, including nightmares
- Changes in memory and concentration
- Flashbacks
- Reactive anger and impulsivity
- Increased fear and anger and decreased positive emotionality
- Difficulty regulating anxiety and anger

III. BEHAVIOR

- Posttraumatic Stress, Depression, Anxiety, & Other Disorders
- Decreased Capacity to Regulation Emotion & Attention
- Impaired Social Development
- Impaired Cognitive Development: IQ, Language
- Poor Academic Performance
- Substance Use/Abuse
- Numbness, Desensitization to Threat
- Subsequent Victimization
- Recklessness & Reenacting Behavior
- Intrusive thoughts, hyperarousal, flashbacks, nightmares, and sleep disturbances, changes in memory and concentration, and startle responses.

(Amaya-Jackson, 2005)

III. REAL LIFE IMPLICATIONS

- Increased stress in caregiver-child relationships
- Increased risk for placement changes
- Behavioral concerns
- Decreased ability to learn
  - Their brains are at capacity trying to cope, understand, and survive, so there is limited capacity to take in new information.
  - Dan Siegel, MD: Flipping Your Lid

IV. SIGNS OF TRAUMA

- Changes in mood, conduct, communication, and/or personality
- Changes in interests, eating, sleeping, toileting, and/or dressing
- Regression to earlier developmental stages or from previously mastered skills
- Avoids specific locations or certain person
- Potential sexualized behaviors
- Unusual gain or loss of weight
- Self-harm or mutilation
- Onset of new fears, such as social anxiety, generalized anxiety, phobias
- Trouble thinking, concentration, remembering
- Re-enactment and somatization

(Nora J. Baladerian, Ph.D., Director, Disabillity and Abuse Project, Trauma and Crime Victim Center of West Los Angeles)

V. WHAT SHOULD YOU CONSIDER WHEN INTERVIEWING YOUR CLIENT?

- Development
  - One of the most important factors in phrasing your questions
  - Chronological age does not always equate emotional/cognitive age (especially for clients who have experienced trauma)
- Culture
  - Family, social network, community and culture influences can impact perception and description of experiences
- Disabilities
  - Collaboration may be needed to successfully interview client
- Need for Psychological Safety

(Angela Tunno, PhD, MS)

V. PSYCHOLOGICAL SAFETY

- Physical safety is not the same as psychological safety
- Client's definition of "safety" might be different than what is expected
- To help clients who have experienced trauma feel safe, you will need to look at the world through his/her "trauma lens"

(Resource Parenting Curriculum, 2010)

V. PROMOTING PSYCHOLOGICAL SAFETY IN CLIENT INTERVIEWS

- Is your setting psychologically safe?
  - How do you greet the client?
  - How is the room arranged?
  - Client friendly furniture and stress-buster tools?
- Rapport-Building is Important
- Question Types
  - Narrative, Open Ended
    - "Tell me what you like to do on weekends.", "What do you like about X?"
  - Directed/Focused
    - "What is your favorite food?"
  - Multiple-Choice
    - "Do you like baseball, soccer, or football?"
  - Yes-No
    - "Do you like running?"
  - Leading/Tag
    - 'You like running better than dancing, don't you?"

V. PROMOTING PSYCHOLOGICAL SAFETY IN CLIENT INTERVIEWS

- Provide and explain structure, including court process and familiarizing client with surroundings
- Inform client of purpose of meeting, what to expect, and duration of meeting
- Work collaboratively with client and allow time for questions and practice, such as role-plays
- Allow the client to have a voice and choice; look for opportunities for active, age-appropriate involvement
- Meet in quiet and client friendly space with minimal distractions
- Be honest regarding potential outcomes of court hearing
- Follow-through with promises
- Quickly and clearly communicate what occurred in court if the client was unable to attend
- Watch for signs of traumatic stress reactions

(Angela Tunno, PhD, MS)

V. REFER TO QUALIFIED PROFESSIONALS

- Refer to trained trauma-informed professionals who can provide:
  - Trauma-informed screening
  - Trauma-informed assessment
  - Evidence-based treatment or an appropriate referral for an evidence-based treatment
  - Resilience

V. TRAUMA-INFORMED SCREENING

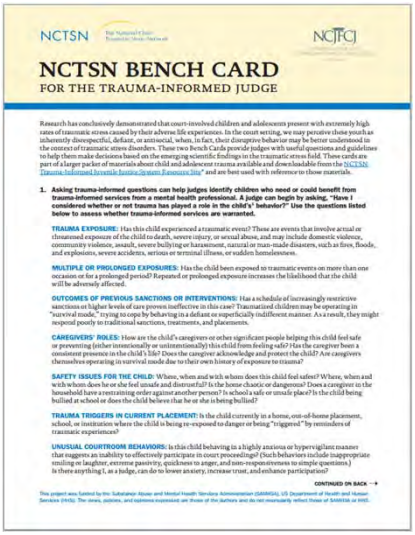
- A brief tool, process, or focused set of questions used to identify whether an individual has experienced one or more traumatic events, has reactions to such events, and needs a referral for a comprehensive trauma-informed assessment.

- May be conducted by front-line staff across various service systems (e.g., child welfare, court, juvenile justice, school personnel, etc.)

V. TRAUMA-INFORMED ASSESSMENT

- Comprehensive assessment process including:
  - Clinical interview
  - Administration of standardized measures
  - And/or behavioral observations
- Understand nature, timing, and severity of the traumatic events, the effects and impact of those events, current trauma-related symptoms, and impairments in cognitive, developmental, and physical functioning
- Used to engage the client and family in a collaborative process to inform case conceptualization and identify treatment planning goals; and to monitor progress over time
- Generally conducted by a mental health professional

V. ADVOCATING FOR TRAUMA-INFORMED ASSESSMENTS



NCTSN NCTFCJ

NCTSN BENCH CARD
FOR THE TRAUMA-INFORMED JUDGE

Research has conclusively demonstrated that court-involved children and adolescents present with extremely high rates of traumatic stress caused by their adverse life experiences. In the court setting, we may perceive these youth as inherently disrespectful, defiant, or antisocial, when, in fact, their disruptive behavior may be better understood in the context of traumatic stress disorders. These two Bench Cards provide judges with useful questions and guidelines to help them make decisions based on the emerging scientific findings in the traumatic stress field. These cards are part of a larger packet of materials about child and adolescent trauma available and downloadable from the NCTSN Trauma-Informed Juvenile Justice System Resource Site and are best used with reference to those materials.

1. **Asking trauma-informed questions can help judges identify children who need or could benefit from trauma-informed services from a mental health professional. A judge can begin by asking, "Have I considered whether or not trauma has played a role in the child's behavior?" Use the questions listed below to assess whether trauma-informed services are warranted.**

TRAUMA EXPOSURE: Has this child experienced a traumatic event? These are events that involve actual or threatened exposure of the child to death, severe injury, or sexual abuse, and may include domestic violence, community violence, assault, severe bullying or harassment, natural or man-made disasters, such as fires, floods, and explosions, severe accidents, serious or terminal illness, or sudden homelessness.

MULTIPLE OR PROLONGED EXPOSURES: Has the child been exposed to traumatic events on more than one occasion or for a prolonged period? Repeated or prolonged exposure increases the likelihood that the child will be adversely affected.

OUTCOMES OF PREVIOUS SANCTIONS OR INTERVENTIONS: Has a schedule of increasingly restrictive sanctions or higher levels of care proven ineffective in this case? Traumatized children may be operating in "survival mode," trying to cope by behaving in a defiant or superficially indifferent manner. As a result, they might respond poorly to traditional sanctions, treatments, and placements.

CAREGIVERS' ROLES: How are the child's caregivers or other significant people helping this child feel safe or preventing (either intentionally or unintentionally) this child from feeling safe? Has the caregiver been a consistent presence in the child's life? Does the caregiver acknowledge and protect the child? Are caregivers themselves operating in survival mode due to their own history of exposure to trauma?

SAFETY ISSUES FOR THE CHILD: Where, when and with whom does this child feel safest? Where, when and with whom does he or she feel unsafe and distrustful? Is the home chaotic or dangerous? Does a caregiver in the household have a restraining order against another person? Is school a safe or unsafe place? Is the child being bullied at school or does the child believe that he or she is being bullied?

TRAUMA TRIGGERS IN CURRENT PLACEMENT: Is the child currently in a home, out-of-home placement, school, or institution where the child is being re-exposed to danger or being "triggered" by reminders of traumatic experiences?

UNUSUAL COURTROOM BEHAVIORS: Is this child behaving in a highly anxious or hypervigilant manner that suggests an inability to effectively participate in court proceedings? (Such behaviors include inappropriate smiling or laughter, extreme passivity, quickness to anger, and non-responsiveness to simple questions.) Is there anything I, as a judge, can do to lower anxiety, increase trust, and enhance participation?

CONTINUED ON BACK →

This project was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), US Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.

- Bench Cards: Tool to advocate for trauma-informed decision making for clients impacted by traumatic stress
  - Developed by NCTSN Justice Consortium and National Council of Juvenile and Family Court Judges

CENTER FOR CHILD & FAMILY HEALTH

V. BENCH CARD #1: QUESTION FOR JUDGES TO CONSIDER

1. Have I considered whether or not trauma plays a role in client's behavior?
2. Do I have complete information from all systems working with the client and family?
3. Am I sufficiently considering trauma as I decide where this client is going to live with and whom?
4. If not enough information, would client and/or caregiver benefit from court-ordered, trauma-informed mental health evaluation?

(NCTSN, Justice Consortium)

V. BENCH CARD #2: WHAT NEEDS TO BE IN TRAUMA-INFORMED ASSESSMENT

- Sample letter to the MH clinician
- Components of Trauma-Informed Assessment Could Include:
  - Assessment of client and caregivers
  - Strengths, Coping Approaches, and Resiliency Factors
  - Rule-In or Rule-Out of Diagnosis of PTSD
  - Identify Trauma-Focused Evidence Based Treatment
  - Informing Placement and Community Supervision Decisions
    - Note: See card for more details.

(NCTSN, Justice Consortium)

V. TRAUMA-INFORMED TREATMENT: WHAT IS EVIDENCE-BASED PRACTICE?

- Sound theoretical basis
- Clinical literature regarding efficacy
- Accepted in clinical practice
- No evidence of substantial harm or risk
- Manual sufficiently detailed to allow for replication
- Efficacy-based on at least two randomized, controlled trials

V. EBT'S IMPLEMENTED IN NC

- Trauma-Focused Cognitive Behavioral Therapy (TF-CBT)
- Child-Parent Psychotherapy (CPP)
- Parent-Child Interaction Therapy (PCIT)
- Attachment Biobehavioral Catch-up (ABD)
- Structured Psychotherapy for Adolescents Responding to Chronic Stress (SPARCS)

- Finding a trained therapist: https://ncchildtreatmentprogram.org/roster.php

V. RESILIENCE

- What is resilience?
  - Ability of client to:
    - Recover and show early and effective adaptation after a potentially traumatic event
    - Respond with minimal distress or impact on daily functioning
    - Return early and effectively to usual functioning from a temporary dip in ability to cope
    - https://www.samhsa.gov/capt/tools-learning-resources/trauma-resilience-resources
- What makes legal advocates and attorneys uniquely effective at promotion of resilience?
  - In a position to:
    - Identify trauma exposure in client, advocate for intervention/prevention efforts, and have ability to gauge strengths of client
    - Focus on and promote client's natural strengths

(Angela Tunno, PhD, MS)

V. RESILIENCE

- What factors might promote resilience after exposure to a traumatic event?
  - External:
    - Support from caregivers/caregivers, friends, school, and community (e.g., strong relationship with caregiver/adult)
    - Resources that buffer negative consequences
    - Feeling safe at home, school, and/or community
  - Internal:
    - Heightened self-esteem and self-worth
    - Sense of self-efficacy
    - Meaning in one's life (e.g., spiritual or cultural beliefs)
    - Talents or skills in certain areas (e.g., art, sports)
    - Adaptive and flexible coping skills

(Angela Tunno, PhD, MS)

VI. IMPACT OF TRAUMA ON THE ATTORNEY-CLIENT RELATIONSHIP

- How could the traumatic stress impact the client-attorney relationship?
  - Difficulty trusting others
  - Difficulty processing information
  - Difficulty communicating (especially in stressful situations)

WHAT IS SECONDARY TRAUMATIC STRESS?

- Secondary traumatic stress (STS) is the emotional and behavioral response that occurs as the result of hearing about the firsthand trauma experiences of another person; it comes from the helper's relationship with a client who has experienced trauma. STS has symptoms similar to PTSD.

OTHER TERMS YOU MAY HEAR USED

- Diagnostically speaking, "burnout," "secondary traumatic stress," "poor work-life balance," and "posttraumatic stress disorder (PTSD)" are not synonymous.
- The terms "vicarious trauma," "compassion fatigue," and "secondary traumatic stress" are sometimes used interchangeably.
  (American Counseling Association, Vicarious Trauma – Fact Sheet #9, 2011)
- Burnout is cumulative, the result of emotional exhaustion due to occupational stress; it comes from the helper's relationship to the institution. Symptoms include lethargy, lack of interest in the job, a reduced feeling of personal accomplishment, emotional fatigue.

HOW CAN LAWYERS EXPERIENCE SECONDARY TRAUMATIC STRESS?

- Generally, anyone working with high-needs clients and families can experience secondary traumatic stress. Specifically, by:
  - Listening to clients' accounts of traumatic events
  - Reading trauma accounts
  - Preparing cases involving trauma accounts
  - Hearing testimony and reviewing other evidence

SYMPTOMS OF SECONDARY TRAUMATIC STRESS

- Re-experiencing personal trauma; intrusive images
- Sleep disorders or nightmares
- Changes in memory or perception
- Difficulty concentrating and focusing
- Increased "jumpiness"
- Hypervigilance; feeling "on edge"; easily startled or upset
- Inability to listen
- Depression
- Avoidance – avoidance of clients; being late to work; calling in sick; missing meetings; avoiding certain questions or topics in client meetings
- Feelings of hopelessness
- Increased physical ailments (e.g., headaches, stomachaches)
- Lowered immunity to illness and disease

(NCTSN, Secondary Traumatic Stress: A Fact Sheet for Child-Service Professionals Segertrom & Miller, 2004)

FACTORS THAT INCREASE THE RISK OF STS

- Personal history and current life circumstances
  - "What's in your suitcase?"
- Clients
- Work environment
- Public perceptions, including media attention

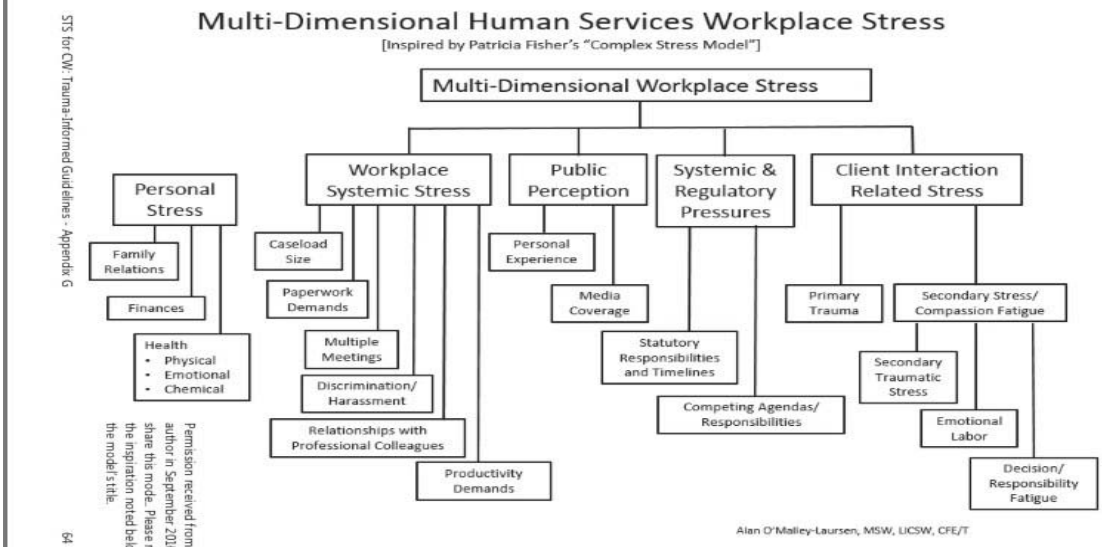
HOW CAN SECONDARY TRAUMATIC STRESS AFFECT WORK AS A LAWYER?

- How attorneys handle their work will be influenced by their own mental health condition, affecting decision-making and service provision.
- Attorneys may:
  - Re-experience traumatic events
  - Feel overwhelmed
  - Feel constantly exhausted
  - Distance themselves from important aspects of their clients' situations
  - Display hypervigilance
  - Feel socially isolated
  - Develop a reputation as hostile, angry, irrational, or erratic, instead of as a zealous advocate
  - Subject themselves to complaints of professional misconduct under the Rules of Professional Conduct

SYMPTOMS AND THE IMPORTANCE OF PROFESSIONAL DIAGNOSIS

Symptoms may be indicative of co-occurring conditions, such as:

- Anxiety Disorders (panic attacks, phobias)
- Acute Stress Disorder
- Depressive Disorder
- Generalized Anxiety Disorder
- Social Anxiety Disorder
- A mood disorder
- A substance-related disorder



THE ABC'S OF PREVENTING AND REDUCING SECONDARY TRAUMATIC STRESS

- A – AWARENESS
- B – BALANCE
- C – CONNECTION

(Jan Williams, LCSW, Center for Child and Family Health)

AWARENESS: LAW OFFICE PRACTICES

- Awareness of STS, from the top down.
- Encouragement and facilitation of peer support and self-care, for individuals and in groups
- Regular debriefing of cases by law office managers
- Caseload reduction for attorneys with high percentages of trauma-related cases
- Organizational promotion of wellness, balance, and self-care
- Regular dissemination of self-assessment surveys and checklists
- Referrals to Lawyer Assistance Programs
- Support attendance at CLEs addressing traumatic stress, or issues such as work-life balance, burnout, and compassion fatigue

BALANCE: INDIVIDUAL ATTORNEY PRACTICES

- Manage your caseloads:
  - Keep the number of cases reasonable
  - Try to balance high-needs cases with lower-needs cases
  - Balancing trauma cases with non-trauma cases is crucial
- Diversify your practice, or shift to other practice areas
- Balance the difficult work with humor and fun (How?)
- Maintain balance between work and home (How?)
- Pursue professional continuing education to learn new skills to effectively meet work demands

BALANCE: INDIVIDUAL ATTORNEY PRACTICES

- Engage in personal self-care:
  - Pamper yourself
  - Take time off (e.g.: vacation time, PTO, mental health days
  - Respite
- Get an assessment from a qualified mental health professional and follow treatment recommendations
- Develop coping strategies
- Learn resilience
- Utilize the State Bar's Lawyer Assistance Program

CONNECTION

- Discussion after a traumatic exposure is important
  - CAVEAT: Discussion should be structured, with all being willing to participate
- Refrain from engaging in one-upmanship about trauma cases, which can increase STS in your colleagues
- Reach out for support from colleagues – don't feel like you have to do it all yourself, or all alone.

SUGGESTED RESOURCES

- National Child Traumatic Stress Network, https://www.nctsn.org/
  - Child Trauma Toolkit for Educators, https://www.nctsn.org/resources/child-trauma-toolkit-educators
  - "Trauma and IDD Toolkit," NCTSN Learning Center, https://learn.nctsn.org/enrol/index.php?id=370
  - "At Intersection of Trauma and Disabilities: A New Toolkit for Providers," NCTSN Learning Center ttps://www.nctsn.org/resources/intersection-trauma-and-disabilities-new-toolkit-providers
- "The Compassion Fatigue Workbook: Creative Tools for Transforming Compassion Fatigue and Vicarious Traumatization," by Francoise Mathieu
- "Secondary Traumatic Stress in Child Welfare Practice, Trauma-Informed Guidelines for Organizations," Appendix G, The Chadwick Center https://www.nctsn.org/sites/default/files/resources/resource-guide/cac_understanding_secondary_traumatic_stress_resources.pdf

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NCTSN The National Child Traumatic Stress Network

Birth Parents with Trauma Histories and the Child Welfare System

A Guide for Resource Parents

THE GARCIAS' STORY

Mr. and Mrs. Garcia, ages 65 and 64, decided to become resource parents[1] three years ago, after their children had grown up and left home. Crystal, age six, and Jonathan, age three, have been with them for six months. Although Crystal is very clingy, they are sweet children, but when they get upset they can be aggressive with each other and almost impossible to calm down. Mrs. Garcia, the primary caretaker, is concerned that there are gaps in the information the foster care agency has given her about their history, their mother Karen, and why the children came into foster care. Mrs. Garcia wonders why every time Karen visits her children she screams at them instead of being happy to see them, which makes them upset and out of control for days afterward.

The children have started to call Mrs. Garcia and her husband "Grandma" and "Grandpa," which she likes, but knows it bothers Karen. She has tried to talk with Karen about how the children are doing; when she drops them off for visits, however, Karen say things under her breath about how her kids didn't act like this when they lived with her. The children ask Mrs. Garcia why they're still in foster care and when they'll be going home; she isn't sure what to tell them. The last time the children hit each other and threatened to hit her, she called the caseworker, who didn't really have an answer for her. Since the last court date, Crystal and Jonathan have been seeing a therapist, but Mrs. Garcia is not sure what they do other than play games. Karen is supposed to join the sessions, but hasn't attended regularly. Mrs. Garcia chose to become a resource parent to help young mothers get their lives together, but from what she can see, she isn't sure that it's best for Crystal and Jonathan to live with Karen again.

Just as children in foster care have lived through trauma, many of their parents have histories of childhood or adult trauma: physical abuse, sexual abuse, domestic violence, serious accidents, and community violence—along with the experience of having their children placed in foster care. These experiences, if left unaddressed, can continue to impact individuals well into adulthood. Parents' past or present trauma can make it difficult for them to work effectively with case workers and resource parents toward reunification with their children. Even if you don't know a parent's personal history of trauma, your recognizing that trauma may have played a role in their lives will help you more effectively support and work with the entire family.

[1] *For the purposes of this fact sheet, "resource parents" refers to foster, adoptive, and kinship parents..*

This project was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), US Department of Health and Human Services (HHS).

What resource parents should know about the effects of trauma on birth parents

A history of traumatic experiences can result in the following:

- Parents may have difficulty keeping themselves and their children safe and healthy. Some are overprotective, while others may not recognize real dangers that can threaten their children.
- Parents may resort to coping in unhealthy ways, such as using drugs or alcohol.
- Parents may react more strongly and/or negatively to things—or have a harder time understanding and/or controlling their emotions, behavior and/or words.
- Parents may be more susceptible to further trauma, such as domestic violence.
- Parents may have an invading sense of loss of control, particularly during and/or directly following their child's removal from home. Often parents will re-experience this during case planning processes, visitation, court hearings, or when they or their child receive services.
- Parents may find it difficult to trust others, especially people in positions of power—caseworkers, judges, and even resource parents.
- Parents may be more vulnerable to trauma reminders—or triggers—when a sound, smell, or feeling brings back the experience of the trauma all over again. Reminders may cause parents to overreact to situations that others would not find difficult. Situations that trigger parents can include:
    - Children's behavior during visits,
    - Case conferences and court hearings, and/or
    - Interactions with resource parents or other authority figures.
- Parents may become numb or shut down—even when interacting with their child—or misread your words or intentions. These difficulties can indicate the presence of trauma reminders.
- Parents may mistrust or be jealous of you as the resource parent. They may second guess your role as caregiver or question your discipline or caretaking choices.

How resource parents can work together with birth parents

A good relationship between birth parents and resource parents promotes child safety, permanence, and well-being. While not easy to do, positive interactions between you and the birth parents can create a sense of safety, security, and support for the children in your care. Particularly in stressful situations, understanding how a history of trauma can impact birth parents can increase your likelihood of success.

Neither birth parents nor resource parents can accomplish their work effectively without the help of the other. Both caregivers bring a unique set of experiences, skills, and knowledge to the process of caring for the child. The following approaches can help you more effectively work with birth parents who have experienced trauma:

- Understanding that parents' anger, fear, resentment, or avoidance may be a reaction to their traumatic experiences—rather than to the child or to you—can help you not to take these reactions personally.

- Remember that parents who have experienced trauma are not "bad," and that blaming or judging them will more likely make the situation worse rather than motivating them to change.
- You can show birth parents that you genuinely care by complimenting their efforts to keep their child safe. Support them in their role as parents by asking for suggestions on how to care for their child. When differences of opinion in parenting beliefs and practices arise, understand that birth parents may be reacting to feelings of fear, inadequacy, or losing control; keep the conversation focused on the child to keep disagreements from becoming personal.

Working with a traumatized birth parent can be more complicated for kinship parents, who often don't have training before becoming foster parents and may have a shared family history of trauma or feelings of shame, anger, responsibility, or guilt related to the parents' and/or child's trauma. Kinship parents may also have a strained relationship with the birth parent related to the parent's involvement with the child welfare system.

- Model direct and honest communication when interacting with birth parents. Share your observations (instead of opinions) when presenting information that may be hard to handle. Similarly, be aware of and openly acknowledge your own mistakes.
- You will want to establish clear boundaries and expectations with birth parents and caseworkers—particularly if you are a kinship provider who is both a foster parent and a relative of the birth parents. Be consistent and, when you make a commitment, follow it through. Work hard to come to agreement, rather than staying stuck on being "right" or trying to "win."
- Remember that visits, court hearings, and case conferences are difficult for birth parents and children. Work with birth parents to set a routine for these encounters: decide together how to handle meetings, say goodbye, schedule phone contacts, and so forth. Tell birth parents and caseworkers about any event that might affect the quality of the meeting (e.g., the child had a tough day at school, didn't sleep well the night before, is coming down with a cold).
- Check your voice tone, body language, and eye contact during stressful situations; if you stay calm, even-toned and neutral, you'll be less likely to generate arguments. If not a kinship provider, always ask the birth parent how they would like to be addressed—this conveys respect.
- Remember that things will not always go smoothly, even if you are trying as hard as you can. Work towards mutual trust, while keeping in mind that it may take some time.

How resource parents can protect themselves from secondary traumatic stress

When resource parents hear about the traumatic events of children or birth parents, they can experience extreme distress or even secondary traumatic stress (also called vicarious trauma or compassion fatigue). If exposed to others' trauma stories, you may have similar stress reactions.

Be aware of how your work as a resource parent can affect you. Try to recognize when you are feeling frustrated or overwhelmed, and identify ways to take care of yourself. Again, kinship parents—who may be more personally impacted by both birth parents' and children's actions and reactions—may have less preparation for foster parenting and a greater need to protect themselves.

When you care for others, you must take time for yourself! Talk to other resource parents, a therapist, or people who have gone through similar experiences to help you keep things in perspective, understand your own reactions, and avoid words or actions that could make the situation worse.

Engaging in self-care can help:

- Make you more effective at accomplishing your goals,
- Give you tools to manage difficult situations as they arise, and
- Provide you with the emotional resources and focus you need to help the child in your care, making you a more effective and fulfilled resource parent.

This fact sheet is one in a series of factsheets discussing parent trauma in the child welfare system. To view others, go to http://www.nctsn.org/trauma-informed-care/trauma-informed-systems/child-welfare/nctsn-resources

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NCTSN The National Child Traumatic Stress Network

Helping Traumatized Children: Tips for Judges

A majority of children involved in the juvenile justice system have a history of trauma.[1] Children and adolescents who come into the court system frequently have experienced not only chronic abuse and neglect, but also exposure to substance abuse, domestic violence, and community violence.[2]

The psychological, emotional, and behavioral consequences of these experiences can be profound, but may go unrecognized if judges and related personnel do not delve more deeply into the backgrounds of children and adolescents who come before the court.[2,3] By understanding the impact of trauma on children's development, beliefs, and behaviors, judges can become more effective in addressing the unique needs and challenges of traumatized children and adolescents involved in the juvenile and family court system.

Effects of Trauma on Children and Adolescents

Child abuse and neglect have been shown to adversely affect the growth of the brain, nervous, and endocrine systems and to impair many aspects of psychosocial development, including the acquisition of social skills, emotional regulation, and respect for societal institutions and mores.[4] Although a significant proportion of traumatized children seen in court meet the diagnostic criteria for posttraumatic stress disorder (PTSD),[5,6] many others suffer from traumatic stress responses that do not meet the clinical definition of PTSD. Traumatic stress may manifest differently in children of different ages. **Table 1** lists some of the most common traumatic stress reactions seen in children of various ages.

Table 1. Child Traumatic Stress Reactions (By Age Group)

Age Group	Common Traumatic Stress Reactions
Young children (Birth–5 y)	▪ Withdrawal and passivity ▪ Exaggerated startle response ▪ Aggressive outbursts ▪ Sleep difficulties (including night terrors) ▪ Separation anxiety ▪ Fear of new situations ▪ Difficulty assessing threats and finding protection (especially in cases where a parent or caretaker was aggressor) ▪ Regression to previous behaviors (e.g., baby talk, bed-wetting, crying)
School-age children (6–12 y)	▪ Abrupt and unpredictable shifts between withdrawn and aggressive behaviors ▪ Social isolation and withdrawal (may be an attempt to avoid further trauma or reminders of past trauma) ▪ Sleep disturbances that interfere with daytime concentration and attention ▪ Preoccupation with the traumatic experience(s) ▪ Intense, specific fears related to the traumatic event(s)
Adolescents (13–18 y)	▪ Increased risk taking (substance abuse, truancy, risky sexual behaviors) ▪ Heightened sensitivity to perceived threats (may respond to seemingly neutral stimuli with aggression or hostility) ▪ Social isolation (belief that they are unique and alone in their pain) ▪ Withdrawal and emotional numbing ▪ Low self esteem (may manifest as a sense of helplessness or hopelessness)

This project was funded by the Substance Abuse and Mental Health Services Administration, US Department of Health and Human Services.

Assessing the Effects of Trauma

Formal trauma assessment is critical to identifying children and adolescents in the courtroom who are suffering from traumatic stress.[2,3] Well-validated trauma screening tools include:

- UCLA PTSD Reaction Index[7]
- Trauma Symptom Checklist for Children (TSCC)[8]
- Trauma Symptom Checklist for Young Children (TSCYC)[9, 10]
- Child Sexual Behavior Inventory[11, 12]

Judges should use professionals experienced in administering and interpreting these assessments to make recommendations to the court.

> In Stark County, the court now understands that when children have been affected by trauma, they are "stuck" in a hypervigilant response. Being constantly on alert to danger decreases the ability of a youth to study and learn. . . They lose their temper and fight with little or no provocation.
>
> For years our court treated these cases as "bad behavior" and "lack of self control." It is only in the last several years that we, as a court, have educated ourselves about trauma. As a result, we now know that it is important to ask about trauma. Indeed, we often discover a history of trauma that has gone undetected, despite attempts to help the child through traditional counseling services.[3]
>
> Judge Michael L. Howard & Robin R. Tener, PhD.

Choosing Appropriate Service Providers

When referring traumatized children and families for care, courts have the unique opportunity to choose practitioners or agencies that understand the impact of trauma on children and can provide evidence-based treatment appropriate to the child's needs.[2]

While treatment needs to be individualized depending on the nature of the trauma a child has experienced, clinicians should use treatments that have clinical research supporting their use. Evidence-based treatment practices are those that have been rigorously studied and found to be effective in treating child or adolescent trauma. Information on specific evidence-based treatments for child traumatic stress is available from:

- The California Evidence-Based Clearinghouse for Child Welfare (http://www.cachildwelfareclearinghouse.org)
- The National Child Traumatic Stress Network– *Empirically Supported Treatments And Promising Practices* (http://www.nctsnet.org/nccts/nav.do?pid=ctr_top_trmnt_prom)
- The National Crime Victims Research and Treatment Center– *Child Physical and Sexual Abuse: Guidelines for Treatment* (http://academicdepartments.musc.edu/ncvc/resources_prof/OVC_guidelines04-26-04.pdf)

Judges may want to develop a list of community providers who have training and experience in delivering evidence-based trauma practices. If the community lacks trained trauma professionals, creating an advisory group that can increase community awareness of evidence-based practices and necessary training requirements might be helpful. It is important to remember that trauma treatment may need to be combined with treatment for other conditions as well, such as substance abuse or learning disabilities. By becoming trauma-informed and encouraging the development and mobilization of trauma-focused interventions, judges can "make the difference between recovery and continued struggle"[3] for traumatized youth and their families.

For More Information On Child Trauma in the Court

The *Juvenile and Family Court Journal* has published two special editions (Winter 2006 and Fall 2008) on child trauma as it relates to dependency and delinquency issues that come before the court. They are available at http://www.ncjfcj.org/content/blogcategory/364/433/.

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National Child Traumatic Stress Network

Established by Congress in 2000, the National Child Traumatic Stress Network (NCTSN) is a unique collaboration of academic and community-based service centers whose mission is to raise the standard of care and increase access to services for traumatized children and their families across the United States. Combining knowledge of child development, expertise in the full range of child traumatic experiences, and attention to cultural perspectives, the NCTSN serves as a national resource for developing and disseminating evidence-based interventions, trauma-informed services, and public and professional education.

Suggested Citation: National Child Traumatic Stress Network, Justice System Consortium. (2009). *Helping Traumatized Children: Tips for Judges*. Los Angeles, CA & Durham, NC: National Center for Child Traumatic Stress.

Dear Judge:

We are pleased to share the NCTSN Bench Card for the Trauma Informed Judge—an official product of the National Child Traumatic Stress Network's Justice Consortium in cooperation with the National Council of Juvenile and Family Court Judges. Designed by judges, lawyers, and behavioral health professionals, this card will assist you in your work with youth who struggle with traumatic stress.

Many court-involved youth have been exposed to traumatic events. They present with problems that require professional assistance to modify their behavior and protect the community. Strong connections have been made between early exposure to trauma and "derailed" child development. Traumatic experiences change the brain in ways that cause youth to think, feel and behave differently.

Trauma impacts many important court decisions, among them:

- temporary placement or custody,
- detention or hospitalization,
- residential or community based treatment,
- treatment and referrals to health and behavioral health services,
- transfers to adult criminal court,
- termination of parental rights and adoption,
- restoration and treatment for child victims,
- visitation with maltreating adults or jail/prison visitation.

For many traumatized children, the judge serves as the crucial professional to direct them to proper treatment. The good news is that, when properly treated through trauma-informed, evidence-based treatment, children can recover.

As a judge, we know you must balance your responsibilities to protect the public and restore victims while also trying to change the destructive life course of a struggling child or an offending teen. Judges know that failure to make such changes can lead to youths who become adults involved in the justice system. Judges often see those adults raise new generations who also appear in court—the outcome of the uninterrupted, intergenerational transmission of traumatic stress.

Enclosed are two bench cards. The first offers a series of questions to help you, as a judge, gather information necessary to make good decisions for children at risk of traumatic stress disorders. The second is a sample addendum designed to be copied or scanned and attached to your orders for behavioral health assessments. It will help mental health professionals develop reports that are trauma informed, admissible into evidence, and informative to you.

We hope that you find the bench cards to be helpful in your work with youth. For additional information and other trauma resources for judges and attorneys, please see http://www.nctsn.org/resources/topics/juvenile-justice-system

Should you have questions regarding the information contained in the cards, please contact Dr. James Clark at clark2j9@UCMAIL.UC.EDU or the NCTSN at help@nctsn.org

Sincerely,
The NCTSN Justice Consortium

NCTSN The National Child Traumatic Stress Network

NCJFCJ NATIONAL COUNCIL OF JUVENILE AND FAMILY COURT JUDGES

NCTSN BENCH CARD

FOR THE TRAUMA-INFORMED JUDGE

Research has conclusively demonstrated that court-involved children and adolescents present with extremely high rates of traumatic stress caused by their adverse life experiences. In the court setting, we may perceive these youth as inherently disrespectful, defiant, or antisocial, when, in fact, their disruptive behavior may be better understood in the context of traumatic stress disorders. These two Bench Cards provide judges with useful questions and guidelines to help them make decisions based on the emerging scientific findings in the traumatic stress field. These cards are part of a larger packet of materials about child and adolescent trauma available and downloadable from the NCTSN Trauma-Informed Juvenile Justice System Resource Site* and are best used with reference to those materials.

1. **Asking trauma-informed questions can help judges identify children who need or could benefit from trauma-informed services from a mental health professional. A judge can begin by asking, "Have I considered whether or not trauma has played a role in the child's[1] behavior?" Use the questions listed below to assess whether trauma-informed services are warranted.**

   TRAUMA EXPOSURE: Has this child experienced a traumatic event? These are events that involve actual or threatened exposure of the child to death, severe injury, or sexual abuse, and may include domestic violence, community violence, assault, severe bullying or harassment, natural or man-made disasters, such as fires, floods, and explosions, severe accidents, serious or terminal illness, or sudden homelessness.

   MULTIPLE OR PROLONGED EXPOSURES: Has the child been exposed to traumatic events on more than one occasion or for a prolonged period? Repeated or prolonged exposure increases the likelihood that the child will be adversely affected.

   OUTCOMES OF PREVIOUS SANCTIONS OR INTERVENTIONS: Has a schedule of increasingly restrictive sanctions or higher levels of care proven ineffective in this case? Traumatized children may be operating in "survival mode," trying to cope by behaving in a defiant or superficially indifferent manner. As a result, they might respond poorly to traditional sanctions, treatments, and placements.

   CAREGIVERS' ROLES: How are the child's caregivers or other significant people helping this child feel safe or preventing (either intentionally or unintentionally) this child from feeling safe? Has the caregiver been a consistent presence in the child's life? Does the caregiver acknowledge and protect the child? Are caregivers themselves operating in survival mode due to their own history of exposure to trauma?

   SAFETY ISSUES FOR THE CHILD: Where, when and with whom does this child feel safest? Where, when and with whom does he or she feel unsafe and distrustful? Is the home chaotic or dangerous? Does a caregiver in the household have a restraining order against another person? Is school a safe or unsafe place? Is the child being bullied at school or does the child believe that he or she is being bullied?

   TRAUMA TRIGGERS IN CURRENT PLACEMENT: Is the child currently in a home, out-of-home placement, school, or institution where the child is being re-exposed to danger or being "triggered" by reminders of traumatic experiences?

   UNUSUAL COURTROOM BEHAVIORS: Is this child behaving in a highly anxious or hypervigilant manner that suggests an inability to effectively participate in court proceedings? (Such behaviors include inappropriate smiling or laughter, extreme passivity, quickness to anger, and non-responsiveness to simple questions.) Is there anything I, as a judge, can do to lower anxiety, increase trust, and enhance participation?

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2. **It is crucial to have complete information from all the systems that are working with the child and family. Asking the questions referenced below can help develop a clearer picture of the child's trauma and assess needs for additional information.**

   COMPLETENESS OF DATA FOR DECISIONS: Has all the relevant information about this child's history been made available to the court, including child welfare and out-of-jurisdiction or out-of-state juvenile justice information?

   INTER-PROFESSIONAL COOPERATION: Who are the professionals who work with this child and family? Are they communicating with each other and working as a team?

   UNUSUAL BEHAVIORS IN THE COMMUNITY: Does this child's behavior make sense in light of currently available information about the child's life? Has the child exhibited extreme or paradoxical reactions to previous assistance or sanctions? Could those reactions be the result of trauma?

   DEVELOPMENT: Is this child experiencing or suffering from emotional or psychological delays? Does the child need to be assessed developmentally?

   PREVIOUS COURT CONTACTS: Has this child been the subject of other court proceedings? (Dependency/Neglect/Abuse; Divorce/Custody; Juvenile Court; Criminal; Other)

   OUT-OF-HOME PLACEMENT HISTORY: How many placements has this child experienced? Have previous placements been disrupted? Were the disruptions caused by reactions related to the child's trauma history? How did child welfare and other relevant professionals manage these disruptions?

   BEHAVIORAL HEALTH HISTORY: Has this child ever received trauma-informed, evidence-based evaluation and treatment? (Well-intentioned psychiatric, psychological, or substance abuse interventions are sometimes ineffective because they overlook the impact of traumatic stress on youth and families.)

3. **Am I sufficiently considering trauma as I decide where this child is going to live and with whom?**

   PLACEMENT OUTCOMES: How might the various placement options affect this child? Will they help the child feel safe and secure and to successfully recover from traumatic stress or loss?

   PLACEMENT RISKS: Is an out-of-home placement or detention truly necessary? Does the benefit outweigh the potential harm of exposing the child to peers who encourage aggression, substance use, and criminal behavior that may possibly lead to further trauma?

   PREVENTION: If placement, detention or hospitalization is required, what can be done to ensure that the child's traumatic stress responses will not be "triggered?" (For example, if placed in isolation or physical restraints, the child may be reminded of previous traumatic experiences.)

   DISCLOSURE: Are there reasons for not informing caregivers or staff at the proposed placement about the child's trauma history? (Will this enhance care or create stigma and re-victimization?)

   TRAUMA-INFORMED APPROACHES: How does the programming at the planned placement employ trauma-informed approaches to monitoring, rehabilitation and treatment? Are staff knowledgeable about recognizing and managing traumatic stress reactions? Are they trained to help children cope with their traumatic reactions?

   POSITIVE RELATIONSHIPS: How does the planned placement enable the child to maintain continuous relationships with supportive adults, siblings or peers?

4. **If you do not have enough information, it may be useful to have a trauma assessment done by a trauma-informed professional. Utilizing the NCTSN BENCH CARD FOR COURT-ORDERED TRAUMA-INFORMED MENTAL HEALTH EVALUATION OF CHILD, you can request information that will assist you in making trauma-informed decisions.**

[1] The use of "child" on this bench card refers to any youth who comes under jurisdiction of the juvenile court.
*http://learn.nctsn.org/course/view.php?id=74

NCTSN The National Child Traumatic Stress Network

NCJFCJ National Council of Juvenile and Family Court Judges

NCTSN BENCH CARD

FOR COURT-ORDERED TRAUMA-INFORMED MENTAL HEALTH EVALUATION OF CHILD: SAMPLE ADDENDUM

This Court has referred this child[1] for mental health assessment. Your report will assist the judge in making important decisions. Please be sure the Court is aware of your professional training and credentials. In addition to your standard psychosocial report, we are seeking trauma-specific information. Please include your opinion regarding the child's current level of danger and risk of harm. The Court is also interested in information about the child's history of prescribed psychiatric medications. We realize that you may be unable to address every issue raised below, but the domains listed below are provided as an evidence-based approach to trauma-informed assessment.

1. SCREENING AND ASSESSMENT OF THE CHILD AND CAREGIVERS

Please describe the interview approaches (structured as well as unstructured) used for the evaluation. Describe the evidence supporting the validity, reliability, and accuracy of these methods for children or adolescents. For screens or tests, please report their validity and reliability, and if they were designed for the population to which this child belongs. If feasible, please report standardized norms.

Discuss any other data that contributed to your picture of this child. Please describe how the perspectives of key adults have been obtained. Are the child's caregivers or other significant adults intentionally or unintentionally preventing this child from feeling safe, worthy of respect, and effective? Are caregivers capable of protecting and fostering the healthy development of the child? Are caregivers operating in "survival mode" (such as interacting with the child in a generally anxious, indifferent, hopeless, or angry way) due to their own history of exposure to trauma? What additional support/resources might help these adults help this child?

2. STRENGTHS, COPING APPROACHES, AND RESILIENCE FACTORS

Please discuss the child's existing strengths and coping approaches that can be reinforced to assist in the recovery or rehabilitation process. Strengths might include perseverance, patience, assertiveness, organization, creativity, and empathy, but coping might take distorted forms. Consider how the child's inherent strengths might have been converted into "survival strategies" that present as non-cooperative or even antisocial behaviors that have brought this child to the attention of the Court.

Please report perspectives voiced by the child, as well as by caregivers and other significant adults, that highlight areas of hope and recovery.

3. DIAGNOSIS (POST TRAUMATIC STRESS DISORDER [PTSD])

Acknowledging that child and adolescent presentations of PTSD symptoms will differ from adult presentations, please "rule-in" or "rule-out" specific DSM-V criteria for PTSD for adolescents and children older than six years, which include the following criteria:

- Exposure to actual or threatened death, serious injury, or sexual violence, either experienced directly, witnessed, or learning that the event occurred to a close family member or friend (Criteria A)
- Presence of intrusion symptoms such as intrusive memories, distressing dreams, flashbacks, physical reactions, trauma-specific re-enactment through play, psychological distress at exposure to cues (Criteria B)
- Avoidance of stimuli or reminders associated with the traumatic event, including avoidance of internal thoughts and feelings related to the event, as well as external activities, places, people, or situations that arouse recollections of the event (Criteria C)

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- Negative changes in cognition, mood, and expectations; diminished interest in, detachment, and estrangement from others; guilt and shame; socially withdrawn behavior; reduction in positive emotions (Criteria D)
- Alterations in arousal and reactivity, including irritable or aggressive behavior, angry outbursts, reckless or self-destructive behavior, hypervigilance, exaggerated startle response, concentration problems, and sleep disturbance (Criteria E)
- Exhibiting these disturbances in behavior, thoughts and mood for over a month (Criteria F)
- Significant distress or impairment in relationships with parents, siblings, peers, or other caregivers or with school behavior (Criteria G)
- The disturbed behavior and mood cannot be attributed to the effects of a medication, street drug, or other medical condition (Criteria H)

PTSD can also be present for children ages six and younger. Criteria include exposure; intrusive symptoms, including distressing memories or play re-enactment and physiological reactions to reminders; avoidance of people, conversations or situations; negative emotional states such as fear, sadness, or confusion, sometimes resulting in constriction of play; irritable behavior and hypervigilance; and impairment in relationships with parents, siblings, peers or other caregivers.

Even if an official DSM-V diagnosis of PTSD is not warranted, traumatic stress reactions can definitely or potentially contribute to the child's behavioral, emotional, interpersonal, or attitudinal problems. Traumatic stress reactions may contribute to problems with aggression, defiance, avoidance, impulsivity, rule-breaking, school failure or truancy, running away, substance abuse, and an inability to trust or maintain cooperative and respectful relationships with peers or adults.

4. TRAUMA-INFORMED SERVICES

Has this child ever received Trauma-Focused, Evidence-Based Treatment?*** Sometimes well-intentioned psychiatric, psychological, social work, or substance abuse evaluations and treatment are incomplete and of limited effectiveness because they do not systematically address the impact of children's traumatic stress reactions.

The Court is interested in potential sources of trauma-informed services in your area and your thoughts about the likelihood that the child can receive those services.

In the meantime, what can be done immediately for and with the family, school, and community to enhance safety, build on the child's strengths, and to provide support and guidance? How can this child best develop alternative coping skills that will help with emotional and behavioral self-regulation?

5. SUGGESTIONS FOR STRUCTURING PROBATION, COMMUNITY SUPERVISION AND/OR PLACEMENT OPTIONS.

Structured case plans for probation, community supervision, and/or placement should consider the ability of the setting and the people involved to assist the child in feeling safe, valued, and respected. This is especially important for traumatized children. Similarly, the plan for returning home, for continuing school and education, and for additional court or probationary monitoring should also clearly address each child's unique concerns about safety, personal effectiveness, self-worth, and respect. Please consider where, when, and with whom this child feels most safe, effective, valued and respected. Where, when, and with whom does the child feel unsafe, ineffective, or not respected? What out-of-home placements are available that can better provide for this child's health and safety, as well as for the community's safety? What placements might encourage success in school, relationships, and personal development?

[1] The use of "child" on this bench card refers to any youth who comes under jurisdiction of the juvenile court.

*** Trauma-Focused, Evidence-Based (TF-EB) Treatment is science-based, often requires training in a specific protocol with careful clinical supervision, and emphasizes the treatment relationship, personal/psychological safety, emotional and behavioral self-regulation, development of coping skills, specific treatment of child traumatic experiences, and development of self-enhancing/pro-social thinking, feeling, decision-making, and behaving. TF-EB treatments include: Trauma-Focused Cognitive Behavioral Therapy, Parent-Child Interaction Therapy, Trauma Affect Regulation: Guidelines for Education and Therapy, Child Parent Psychotherapy and more. See website: http://www.nctsn.org/resources/topics/treatments-that-work/promising-practices

NCTSN The National Child Traumatic Stress Network

"...We are stewards not just of those who allow us into their lives but of our own capacity to be helpful..."[1]

Secondary Traumatic Stress

A Fact Sheet for Child-Serving Professionals

INTRODUCTION

Each year more than 10 million children in the United States endure the trauma of abuse, violence, natural disasters, and other adverse events.[2] These experiences can give rise to significant emotional and behavioral problems that can profoundly disrupt the children's lives and bring them in contact with child-serving systems. For therapists, child welfare workers, case managers, and other helping professionals involved in the care of traumatized children and their families, the essential act of listening to trauma stories may take an emotional toll that compromises professional functioning and diminishes quality of life. Individual and supervisory awareness of the impact of this indirect trauma exposure—referred to as secondary traumatic stress—is a basic part of protecting the health of the worker and ensuring that children consistently receive the best possible care from those who are committed to helping them.

Our main goal in preparing this fact sheet is to provide a concise overview of secondary traumatic stress and its potential impact on child-serving professionals. We also outline options for assessment, prevention, and interventions relevant to secondary stress, and describe the elements necessary for transforming child-serving organizations and agencies into systems that also support worker resiliency.

TABLE OF CONTENTS

Intoduction..... 1

SECTION ONE:
How Individuals Experience
Secondary Traumatic Stress ?.....2

SECTION TWO:
Understanding Who is at Risk.....2

SECTION THREE:
Identifying Secondary Traumatic Stress 3

SECTION FOUR:
Strategies for Prevention.....3

SECTION FIVE:
Strategies for Intervention.....4

SECTION SIX:
Worker Resiliency in Trauma-informed
Systems: Essential Elements.....5

1 How Individuals Experience Secondary Traumatic Stress

Secondary traumatic stress is the emotional duress that results when an individual hears about the firsthand trauma experiences of another. Its symptoms mimic those of post-traumatic stress disorder (PTSD). Accordingly, individuals affected by secondary stress may find themselves re-experiencing personal trauma or notice an increase in arousal and avoidance reactions related to the indirect trauma exposure. They may also experience changes in memory and perception; alterations in their sense of self-efficacy; a depletion of personal resources; and disruption in their perceptions of safety, trust, and independence. A partial list of symptoms and conditions associated with secondary traumatic stress includes[3]

- **Hypervigilance**
- **Hopelessness**
- **Inability to embrace complexity**
- **Inability to listen, avoidance of clients**
- **Anger and cynicism**
- **Sleeplessness**
- **Fear**
- **Chronic exhaustion**
- **Physical ailments**
- **Minimizing**
- **Guilt**

Clearly, client care can be compromised if the therapist is emotionally depleted or cognitively affected by secondary trauma. Some traumatized professionals, believing they can no longer be of service to their clients, end up leaving their jobs or the serving field altogether. Several studies have shown that the development of secondary traumatic stress often predicts that the helping professional will eventually leave the field for another type of work.[4,5]

2 Understanding Who is at Risk

The development of secondary traumatic stress is recognized as a common occupational hazard for professionals working with traumatized children. Studies show that from 6% to 26% of therapists working with traumatized populations,and up to 50% of child welfare workers, are at high risk of secondary traumatic stress or the related conditions of PTSD and vicarious trauma.

Any professional who works directly with traumatized children, and is in a position to hear the recounting of traumatic experiences, is at risk of secondary traumatic stress. That being said, risk appears to be greater among women and among individuals who are highly empathetic by nature or have unresolved personal trauma. Risk is also higher for professionals who carry a heavy caseload of traumatized children; are socially or organizationally isolated; or feel professionally compromised due to inadequate training.[6,8] Protecting against the development of secondary traumatic stress are factors such as longer duration of professional experience, and the use of evidence-based practices in the course of providing care.[7]

Secondary Traumatic Stress and Related Conditions: Sorting One from Another

Secondary traumatic stress refers to the presence of PTSD symptoms caused by at least one indirect exposure to traumatic material. Several other terms capture elements of this definition but are not all interchangeable with it.

Compassion fatigue, a label proposed by Figley4 as a less stigmatizing way to describe secondary traumatic stress, has been used interchangeably with that term.

Vicarious trauma refers to changes in the inner experience of the therapist resulting from empathic engagement with a traumatized client.[13] It is a theoretical term that focuses less on trauma symptoms and more on the covert cognitive changes that occur following cumulative exposure to another person's traumatic material. The primary symptoms of vicarious trauma are disturbances in the professional's cognitive frame of reference in the areas of trust, safety, control, esteem, and intimacy.

Burnout is characterized by emotional exhaustion, depersonalization, and a reduced feeling of personal accomplishment. While it is also work-related, burnout develops as a result of general occupational stress; the term is not used to describe the effects of indirect trauma exposure specifically.

Compassion satisfaction refers to the positive feelings derived from competent performance as a trauma professional. It is characterized by positive relationships with colleagues, and the conviction that one's work makes a meaningful contribution to clients and society.

3 Identifying Secondary Traumatic Stress

Supervisors and organizational leaders in child-serving systems may utilize a variety of assessment strategies to help them identify and address secondary traumatic stress affecting staff members.

The most widely used approaches are informal self-assessment strategies, usually employed in conjunction with formal or informal education for the worker on the impact of secondary traumatic stress. These self-assessment tools, administered in the form of questionnaires, checklists, or scales, help characterize the individual's trauma history, emotional relationship with work and the work environment, and symptoms or experiences that may be associated with traumatic stress.[4,9]

Supervisors might also assess secondary stress as part of a reflective supervision model. This type of supervision fosters professional and personal development within the context of a supervisory relationship. It is attentive to the emotional content of the work at hand and to the professional's responses as they affect interactions with clients. The reflective model promotes greater awareness of the impact of indirect trauma exposure, and it can provide a structure for screening for emerging signs of secondary traumatic stress. Moreover, because the model supports consistent attention to secondary stress, it gives supervisors and managers an ongoing opportunity to develop policy and procedures for stress-related issues as they arise.

Formal assessment of secondary traumatic stress and the related conditions of burnout, compassion fatigue, and compassion satisfaction is often conducted through use of the Professional Quality of Life Measure (ProQOL).[7,8,10,11] This questionnaire has been adapted to measure symptoms and behaviors reflective of secondary stress. The ProQOL can be used at regular intervals to track changes over time, especially when strategies for prevention or intervention are being tried.

4 Strategies for Prevention

A multidimensional approach to prevention and intervention—involving the individual, supervisors, and organizational policy—will yield the most positive outcomes for those affected by secondary traumatic stress. The most important strategy for preventing the development of secondary traumatic stress is the triad of psychoeducation, skills training, and supervision. As workers gain knowledge and awareness of the hazards of indirect trauma exposure, they become empowered to explore and utilize prevention strategies to both reduce their risk and increase their resiliency to secondary stress. Preventive strategies may include self-report assessments, participation in self-care groups in the workplace, caseload balancing, use of flextime scheduling, and use of the self-care accountability buddy system. Proper rest, nutrition, exercise, and stress reduction activities are also important in preventing secondary traumatic stress.

PREVENTION

- **Psychoeducation**
- **Clinical supervision**
- **Ongoing skills training**
- **Informal/formal self-report screening**
- **Workplace self-care groups**
  (for example, yoga or meditation)
- **Creation of a balanced caseload**
- **Flextime scheduling**
- **Self-care accountability buddy system**
- **Use of evidence-based practices**
- **Exercise and good nutrition**

5 Strategies for Intervention

Although evidence regarding the effectiveness of interventions in secondary traumatic stress is limited, cognitive-behavioral strategies and mindfulness-based methods are emerging as best practices. In addition, caseload management, training, reflective supervision, and peer supervision or external group processing have been shown to reduce the impact of secondary traumaticstress. Many organizations make referrals for formal intervention from outside providers such as individual therapists or Employee Assistance Programs. External group supervision services may be especially important in cases of disasters or community violence where a large number of staff have been affected.

The following books, workbooks, articles, and self-assessment tests are valuable resources for further information on self-care and the management of secondary traumatic stress:

- Volk, K.T., Guarino, K., Edson Grandin, M., & Clervil, R. (2008). *What about You? A Workbook for Those Who Work with Others.* The National Center on Family Homelessness. http://508.center4si.com/SelfCare-forCareGivers.pdf
- *Self-Care Assessment Worksheet* http://www.ecu.edu/cs-dhs/rehb/uploa Wellness_Assessment.pdf
- Hopkins, K. M., Cohen-Callow, A., Kim, H. J., Hwang, J. (2010). Beyond intent to leave: Using multiple outcome measures for assessing turnover in child welfare. *Children and Youth Services Review, 32*,1380-1387.
- Saakvitne, K. W., Pearlman, L. A., & Staff of TSI/CAAP. (1996). *Transforming the Pain: A Workbook on Vicarious Traumatization.* New York: W.W. Norton.
- Van Dernoot Lipsky, L. (2009). *Trauma Stewardship: An everyday guide to caring for self while caring for others.* San Francisco: Berrett-Koehler Publishers.
- Compassion Fatigue Self Test http://www.ptsdsupport.net/compassion_fatugue-selftest.html
- *ProQOL 5* http://proqol.org/ProQol_Test.html
- Rothschild, B. (2006). *Help for the helper. The psychophysiology of compassion fatigue and vicarious trauma.* New York: W.W. Norton.

INTERVENTION

Strategies to evaluate secondary stress

Cognitive behavioral interventions

Mindfulness training

Reflective supervision

Caseload adjustment

Informal gatherings following crisis events (to allow for voluntary, spontaneous discussions)

Change in job assignment or workgroup

Referrals to Employee Assistance Programs or outside agencies

6 Worker Resiliency in Trauma-informed Systems: Essential Elements

Both preventive and interventional strategies for secondary traumatic stress should be implemented as part of an organizational risk-management policy or task force that recognizes the scope and consequences of the condition. The Secondary Traumatic Stress Committee of the National Child Traumatic Stress Network has identified the following concepts as essential for creating a trauma-informed system that will adequately address secondary traumatic stress. Specifically, the trauma-informed system must

- Recognize the impact of secondary trauma on the workforce.
- Recognize that exposure to trauma is a risk of the job of serving traumatized children and families.
- Understand that trauma can shape the culture of organizations in the same way that trauma shapes the world view of individuals.
- Understand that a traumatized organization is less likely to effectively identify its clients' past trauma or mitigate or prevent future trauma.
- Develop the capacity to translate trauma-related knowledge into meaningful action, policy, and improvements in practices.

These elements should be integrated into direct services, programs, policies, and procedures, staff development and training, and other activities directed at secondary traumatic stress.

> *"We have an obligation to our clients, as well as to ourselves, our colleagues and our loved ones, not to be damaged by the work we do."*[12]

This project was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), US Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.

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NCTSN The National Child Traumatic Stress Network

About the National Child Traumatic Stress Network

Established by Congress in 2000, the National Child Traumatic Stress Network (NCTSN) is a unique collaboration of academic and community-based service centers whose mission is to raise the standard of care and increase access to services for traumatized children and their families across the United States. Combining knowledge of child development, expertise in the full range of child traumatic experiences, and attention to cultural perspectives, the NCTSN serves as a national resource for developing and disseminating evidence-based interventions, trauma-informed services, and public and professional education.

Self-Care Inventory

Rate the following areas in frequency:

5 = frequently
4 = occasionally
3 = rarely
2 = never
1 = it never occurred to me

Physical Self-Care	5	4	3	2	1
Eat regularly (e.g. breakfast, lunch and dinner)					
Eat healthy foods					
Exercise consistently					
Get regular medical care for prevention					
Get medical care when necessary					
Take time off when sick					
Dance, swim, walk, run, play sports, sing or do some other physical activity that is enjoyable to self					
Take time to be sexual					
Get enough sleep					
Take vacations					
Wear clothes you like					
Take day trips or mini-vacations					
Make time away from telephones					
Other:					

Psychological Self-Care	5	4	3	2	1
Make time for self-reflection					
Engage in personal psychotherapy					
Write in a journal					
Read literature that is unrelated to work					
Do something in which you are not an expert or in charge					
Cope with stress in personal and/or work life					
Notice inner experience (e.g. listen to and recognize thoughts, judgments, beliefs, attitudes and feelings)					
Provide others with different aspects of self (e.g. communicate needs and wants)					
Try new things					
Practice receiving from others					
Improve ability to say “no” to extra responsibilities					
Other:					

Emotional Self-Care	5	4	3	2	1
Allow for quality time with others whose company you enjoy					
Maintain contact with valued others					
Give self affirmations and praise					
Love self					
Reread favorite book or review favorite movies					
Identify and engage in comforting activities, objects, people, relationships and places					
Allow for feeling expression (laugh, cry, etc.…)					
Other:					

Spiritual Self-Care	5	4	3	2	1
Allow time for reflection					
Spend time with nature					
Participate in a spiritual community					
Open to inspiration					
Cherish own optimism and hope					
Be aware of nonmaterial aspects of life					
Cultivate ability to identify what is meaningful and its place in personal life					
Meditate/pray					
Contribute to causes in which you believe					
Read inspirational literatures (lectures, music, etc.)					
Other:					

Workplace or Professional Self-Care	5	4	3	2	1
Allow for breaks during the workday					
Engage with co-workers					
Provide self quiet time/space to complete tasks					
Participate in projects or tasks that are exciting and rewarding					
Set limits/boundaries with clients and colleagues					
Balance workload/cases					
Arrange work space for comfort					
Maintain regular supervision or consultation					
Negotiate needs (benefits, bonuses, raise, etc.)					
Participate in peer support group					
Other:					

Adapted from Child Welfare Training Toolkit, March 2008. Original source unknown

YOUR HEALTHIEST SELF

Social Wellness Checklist

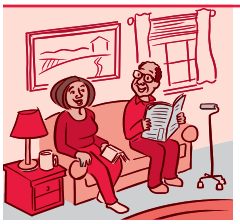
Positive social habits can help you build support systems and stay healthier mentally and physically. Here are some tips for connecting with others:

MAKE CONNECTIONS

Social connections might help protect health and lengthen life. Scientists are finding that our links to others can have powerful effects on our health. Whether with family, friends, neighbors, romantic partners, or others, social connections can influence our biology and well-being. Look for ways to get involved with others.

To find new social connections:

- ☐ Join a group focused on a favorite hobby.
- ☐ Take a class to try something new.
- ☐ Try yoga, tai chi, or another new physical activity.
- ☐ Join a choral group, theater troupe, band, or orchestra.
- ☐ Help at a community garden or park.
- ☐ Volunteer at a school, library, or hospital.
- ☐ Participate in neighborhood events.
- ☐ Join a local community group.
- ☐ Travel to different places and meet new people.



TAKE CARE OF YOURSELF WHILE CARING FOR OTHERS

Many of us will end up becoming a caregiver at some point in our lives. The stress and strain of caregiving can take a toll on your health. It's important to find ways to care for your health while caring for others. Depending on your circumstances, some self-care strategies may be more difficult to carry out than others. Choose ones that work for you.

To take care of yourself while caring for others:

- ☐ Ask for help. Make a list of ways others can help. For instance, someone might sit with the person while you do errands.
- ☐ Make to-do lists, and set a daily routine.
- ☐ Try to take breaks each day.
- ☐ Keep up with your hobbies and interests when you can.
- ☐ Join a caregiver's support group.
- ☐ Eat healthy foods, and exercise as often as you can.
- ☐ Build your caregiver skills. Some hospitals offer classes on how to care for someone with an injury or illness.

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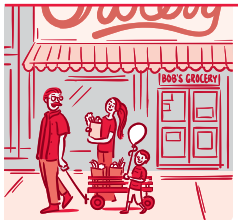

GET ACTIVE TOGETHER

Where you live, work, or go to school can have a big impact on how much you move and even how much you weigh. Being active with others in your community can have a positive effect on your health habits and create opportunities to connect. You can help your community create ways to encourage more physical activity.

To help make a more active community:

- ☐ Start a walking group with friends.
- ☐ Drive the speed limit and yield to people who walk.
- ☐ Consider joining an exercise group.
- ☐ Participate in local planning efforts to develop walking paths, sidewalks, and bike paths.
- ☐ Join other parents to ask for more physical activity at school.
- ☐ Try different activities!

SHAPE YOUR FAMILY'S HEALTH HABITS

Many things can influence a child, including friends, teachers, and the things they see when they sit in front of the TV or computer. If you're a parent, know that your everyday behavior plays a big part in shaping your child's behavior, too. With your help, kids can learn to develop healthy eating and physical activity habits that last throughout their lives.

To help kids form healthy habits:

- ☐ Be a role model. Choose healthy food and activities when together.
- ☐ Make healthy choices easy. Have nutritious food and sports gear readily available.
- ☐ Focus on making healthy habits fun.
- ☐ Limit screen time.
- ☐ Check with caregivers or schools to be sure they offer healthy food and activities.
- ☐ Change a little at a time.

BOND WITH YOUR KIDS

Parents have an important job. Raising kids is both rewarding and challenging. Being sensitive, responsive, consistent, and available to your kids can help you build positive, healthy relationships with them. The strong emotional bonds that result help children learn how to manage their own feelings and behaviors and develop self-confidence. Children with strong connections to their caregivers are more likely to be able to cope with life's challenges.

To build strong relationships with your kids:

- ☐ Catch kids showing good behavior and offer specific praise.
- ☐ Give children meaningful jobs at home and positive recognition afterward.
- ☐ Use kind words, tones, and gestures.
- ☐ Spend some time every day in warm, positive, loving interaction with your kids.
- ☐ Brainstorm solutions to problems together.
- ☐ Set rules for yourself for mobile devices and other distractions.
- ☐ Ask about your child's concerns, worries, goals, and ideas.
- ☐ Participate in activities your child enjoys.

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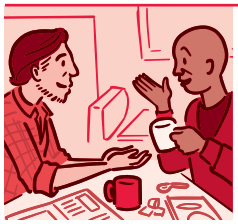

BUILD HEALTHY RELATIONSHIPS

Strong, healthy relationships are important throughout your life. They can impact your mental and physical well-being. As a child you learn the social skills you need to form and maintain relationships with others. But at any age you can learn ways to improve your relationships. It's important to know what a healthy relationship looks like and how to keep your connections supportive.

To build healthy relationships:

- ☐ Share your feelings honestly.
- ☐ Ask for what you need from others.
- ☐ Listen to others without judgement or blame. Be caring and empathetic.
- ☐ Disagree with others respectfully. Conflicts should not turn into personal attacks.
- ☐ Avoid being overly critical, angry outbursts, and violent behavior.
- ☐ Expect others to treat you with respect and honesty in return.
- ☐ Compromise. Try to come to agreements that work for everyone.
- ☐ Protect yourself from violent and abusive people. Set boundaries with others. Decide what you are and aren't willing to do. It's okay to say no.
- ☐ Learn the differences between healthy, unhealthy, and abusive ways of relating to others. Visit www.thehotline.org/healthy-relationships/relationship-spectrum.

NCTSN The National Child Traumatic Stress Network

ABA Center on Children and the Law
AMERICAN BAR ASSOCIATION

TRAUMA:
What Child Welfare Attorneys Should Know

EXECUTIVE SUMMARY

Each year, over 45 million children in the United States are affected by violence, crime, abuse, or psychological trauma.[1] Trauma exposure can significantly interfere with the way children's brains assess threat, which in turn can affect how they respond to stress. The negative impact of trauma exposure is particularly relevant for children and families in the child welfare system, as the majority of child welfare-involved clients have experienced multiple traumas, including abuse, neglect, and exposure to domestic violence. By understanding the impact of trauma on youth and families, and incorporating trauma-informed skills into legal advocacy, attorneys representing children or parents in child welfare cases can improve outcomes for their clients.

This document is intended to provide you with knowledge about the impact of trauma, practice tips for incorporating trauma-informed practices into legal representation, and resources to assist in the representation of clients with histories of trauma. Its intent is to guide you in your representation of clients, with the understanding that not all suggestions will be applicable or appropriate in all cases.

Trauma-informed legal practice can strengthen legal advocacy, improve attorney-client relationships, and ensure appropriate screening, in-depth assessment, and evidence-based treatment. In addition, awareness of secondary traumatic stress can improve prevention, identification, and self-care among legal professionals.

Below is a summary of tips that may assist you in incorporating trauma-informed skills and principles into your everyday practice. More detailed information about each of these tips can be found in the document that follows.

TABLE OF CONTENTS

Executive Summary..... 1

SECTION ONE:
Defining Trauma-Informed Legal Advocacy
.....4

SECTION TWO:
The Impact of Trauma Exposure
on Child Development.....5

SECTION THREE:
The Impact of Trauma Exposure
on Parents 6

SECTION FOUR:
The Impact of Trauma on the
Attorney-Client Relationship 8

SECTION FIVE:
Screening and Assessment.....11

SECTION SIX:
Effective Treatments for Traumatic Stress
.....12

SECTION SEVEN:
Transitions, Placement Decisions,
and Visitation 13

SECTION EIGHT:
Secondary Traumatic Stress
and Attorneys 15

SECTION NINE:
The Importance of Collaboration 17

SECTION TEN:
Systems-Level Advocacy and Resources....19

PRACTICE TIPS

General Tips for Representing Clients in Child Welfare Cases

- Identify known or suspected trauma the client may have experienced.
- Consider the role trauma exposure may play in a client's behaviors, including refusal to engage in treatment, missing court appearances or appointments, as well as exhibiting hostility, apathy, or defiance during court proceedings. These behaviors could be misinterpreted signs of an alarm reaction or trauma response.
- Provide structure, predictability, and opportunities for the client to exert control over decisions as appropriate.
- Provide adequate explanation to the client about his case, including your role as the attorney, a reasonable understanding of the purpose of court proceedings, and a realistic expectation of the potential outcome of court proceedings.
- Advocate for placement stability for children. When placement change is necessary, advocate for a planned transition that occurs gradually rather than abruptly.
- Advocate for visitation to begin immediately between child and parent, unless this poses a threat to the child's physical or psychological safety or the child does not want visitation.
- Support visitation that is intentional, well-planned, and held in a neutral location away from where the trauma occurred. Make every effort to prepare the child for visitation.
- Encourage continuity of treatment after transitions and collaboration among professionals providing services for the client.
- Promote client resilience by leveraging existing social supports, advocating for client involvement in services and activities that increase a sense of mastery and competence, and making referrals for trauma-informed mental health treatment when appropriate.

Trauma Screening, Assessment, and Treatment

- Advocate for universal screening of trauma exposure and related symptoms.
- Provide universal in-depth assessment for those children and parents for whom a screening identifies a history of trauma.
- Make referrals or advocate for appropriate trauma treatment for clients affected by trauma exposure. Not all mental health providers are trained to provide evidence-based trauma treatment, so it is important to identify the type of treatment offered.
- Coordinate with a client's existing therapist to ascertain information about trauma triggers, suggested steps for ameliorating trauma triggers, the treatment being provided, and any other relevant information, such as risk for self-harm.

Attorney-Client Relationship

- Consider issues of physical and psychological safety when advocating for clients and resist practices that may re-traumatize children and parents.
- Meet in a quiet space with minimal distractions and outside the presence of other parties who may contribute to the client feeling threatened.
- Provide adequate information about the attorney-client meeting, including the purpose of the meeting, expectations for the meeting, and length of the meeting.
- Provide a thorough explanation about the court process, including the purpose of each court hearing, the information that you will present in court, and potential questions that the judge or attorneys may ask of the client. Allow the client time to practice and role-play responses.
- Be alert for signs of a trauma reaction, which typically present as some variation of the fight, flight, or freeze response. These signs may include lashing out, shutting down or withdrawing, or regressive, defiant, or disrespectful behaviors.
- Try to avoid startling the client with loud noises, sudden movements, or unexpected news without adequate explanation or preparation.
- Minimize touching the client, which can trigger a reaction in individuals with histories of physical or sexual abuse.
- Avoid overpromising or telling the client that "everything will be fine." Clients may be triggered by feeling let down or misled by their attorney.

Secondary Traumatic Stress

- Maintain work environments for staff that increase resilience and acknowledge, reduce, and treat vicarious or secondary traumatic stress.
- Identify and engage in self-care on an individual and organizational basis.

TRAUMA:
What Child Welfare Attorneys Should Know

1 Defining Trauma-Informed Legal Advocacy

In 2014, more than 700,000 children in the United States were exposed to child maltreatment and more than 400,000 children were residing in foster care.[1] Children in foster care are likely to have been exposed to multiple forms of trauma, such as physical or sexual abuse, neglect, family and/or community violence, trafficking or commercial sexual exploitation, bullying, or loss of loved ones. [2] In addition to situations of abuse or neglect that lead to their removal from their homes, children in care may experience further stresses after entering the system. Separation from family, friends, and community is often referred to as system-induced trauma.

The majority of parents or caregivers involved in the child welfare system have also experienced trauma and many were maltreated or placed in foster care as children. Addressing trauma among families involved in child welfare is essential to stopping this cycle of maltreatment. Without proper intervention, the negative effects of childhood trauma may persist into adulthood, and can result in higher rates of psychiatric or medical illness, substance use, criminal offending, and early death.[3]

The Attorney General's National Task Force on Children Exposed to Violence1 recommends that all professionals serving children exposed to violence and psychological trauma learn about and provide for trauma-informed care and trauma-focused services. Similarly, the American Bar Association has called for integrating trauma knowledge into daily legal practice and integrating and sustaining trauma awareness and skills in practice and policies.[4]

Trauma-informed systems are structured with an understanding of the causes and effects of traumatic experiences, and incorporate practices that support recovery. [5] A system-wide approach requires involvement by all stakeholders working with children and their families, including caseworkers, attorneys for all parties, judges, service providers, birth parents, and caregivers such as foster parents and kinship caregivers.

By enhancing the ability to recognize the impact of trauma, respond appropriately, and avoid legal practices that may re-traumatize children or parents, trauma-informed legal representation can support recovery and enhance resilience, thus improving outcomes for children and families. Incorporating trauma-informed skills into legal practice can also improve attorney-client relationships, increase opportunities to advocate for appropriate services, and enhance prevention, recognition, and mitigation of secondary traumatic stress (STS; see Section Eight).

Trauma-informed legal representation may include:

1. Identifying all known and suspected trauma the client may have experienced
2. Understanding parent and caregiver trauma and its impact on the family
3. Considering the legal implications of routine screening for trauma exposure and related symptoms, particularly for parents and dual-system involved youth (see Glossary)
4. Making appropriate referrals for culturally sensitive, evidence-based assessment and treatment for traumatic stress and associated mental health symptoms
5. Advocating for provision of resources (e.g., psychoeducational books, victim assistance information) about trauma exposure, its impact, and treatment for children, families, and stakeholders
6. Understanding and promoting resilience and protective factors for children and their families
7. Encouraging continuity of care and collaboration across child-serving systems
8. Maintaining work environments for staff that increase staff resilience and address, reduce, and treat vicarious or secondary traumatic stress
9. Considering issues of physical and psychological safety when advocating for clients and resisting practices that may re-traumatize children and parents
10. Maintaining awareness of one's own behaviors, tone of voice, body language, and approach when engaging and questioning clients who may have a history of trauma
11. Taking steps to make clients more comfortable and to recognize when clients are having a trauma reaction
12. Engaging in continuing education about trauma to learn new and developing information that can benefit clients

These suggestions identify actions you can take to promote a trauma-informed response to your clients, *with the understanding that the confines of professional conduct, including confidentiality and ethical considerations as well as strategic case planning, may affect one's ability to act on these recommendations in individual cases.* In addition, advocates should always clearly explain their role to child clients, whether they are representing the client's expressed wishes as an attorney, best interest as *guardian ad litem*, or taking a hybrid approach.

By keeping these principles in mind, you can build more effective relationships with your clients to serve their legal interests, work to ensure necessary service needs are met, and support clients' current and future well-being.

2 The Impact of Trauma Exposure on Child Development

Approximately 80 to 90 percent of youth involved in the child welfare system have experienced at least one traumatic event.[6] Trauma may result from either direct experiences, such as being neglected or abused, or witnessed experiences including domestic violence between caregivers. Children may also be traumatized by hearing about something that happened to their parent or caregiver (e.g., serious injury, incarceration).[7]

Traumatic experiences early in life may alter how the brain assesses threat and how clients respond to stress. A fight or flight response may be "triggered" by anything that reminds a client of past traumatic events, causing a perception of immediate danger. A triggered youth or adult may engage in aggressive or avoidant behaviors in an effort to feel safe; behave defiantly or aggressively to keep others at a distance; or attempt to escape the situation. Common responses include running away from home or school; avoiding attorneys or court hearings perceived as threatening; shutting down; or "spacing out."

There are a range of potential reactions to traumatic events. Most trauma survivors, including youth in the juvenile justice system or parents accused of maltreatment, will recover from their experiences and thus should not be viewed as "damaged" or beyond help. Trauma's impact on the brain and normal child development can be reversed with appropriate treatment and other supports (see Section Six). Recovery is related to resilience; and attorneys can promote clients' resilience in a number of ways, listed below.

PRACTICE TIPS: PROMOTING CLIENT RESILIENCE

Leverage existing social supports – immediate and extended family, fictive kin (see Glossary Terms, page X), community and religious leaders, school staff, coaches, etc.

Advocate for clients' involvement in services or activities that increase their sense of mastery or competence, such as parenting classes/training for caregivers, or afterschool activities for children and youth.

Support clients in developing effective coping skills by referring them to trauma-informed treatment as indicated, and helping them cope with potentially distressing court proceedings or transitions by adequately explaining them in advance.

While many youth and adults who experience trauma are able to work through subsequent challenges without professional intervention, some will develop symptoms of Posttraumatic Stress Disorder, or PTSD (see Glossary Terms, page 6, for definition). PTSD increases the risk for negative outcomes across the lifespan, including academic challenges and peer problems in childhood and criminal justice involvement in adolescence and adulthood. (See Appendix, Section Two, for additional resources on how trauma may affect clients in different age groups.) Some clients may experience partial symptoms of PTSD or develop other disorders such as substance use, depression, or anxiety.

Many trauma survivors will not meet criteria for a PTSD diagnosis but will experience significant trauma-related impairment in daily living. Youth or adults with more chronic or pervasive exposure to traumatic events, termed complex trauma, may suffer additional challenges that are not captured by the PTSD diagnosis (see Glossary Terms). Whenever possible, clients should be screened. If a trauma screen reveals trauma exposure, a further in-depth assessment for trauma exposure and related symptoms to determine the impact of their traumatic experiences and need for appropriate treatment is warranted (see Section Five).

3 The Impact of Trauma Exposure on Child Development

Approximately 90 percent of parents or caregivers involved in the child welfare system have histories of trauma exposure, including high rates of childhood abuse and neglect, and a significant number were involved in the system as children.[8,9,10] Additionally, families may be affected by historical trauma resulting from societal racism and oppression towards ethnic minorities, particularly African-American, Native American, and immigrant communities. The impact of these traumatic experiences on both caregivers and their children can be inadvertently intensified by institutional practices within systems such as child welfare or juvenile justice.[11]

Exposure to trauma does not always determine adverse outcomes for parents and their children. However, for some parents, prior trauma exposure may negatively impact the manner in which they interact with their children, thereby placing children at higher risk for traumatic stress. This is also known as intergenerational trauma. For example, parents with histories of repeated exposure to violence may have greater difficulty recognizing the adverse effects of violence exposure for children. Untreated PTSD can also interfere with a parent's ability to use safe and effective parenting strategies and protect their children from abuse by others.[12,13] In turn, without effective intervention, children exposed to neglect or abuse are significantly more likely to perpetrate violence against dating partners, enter into abusive relationships in adolescence and adulthood, and perpetrate abuse of their own children when they become parents.[14,15,16] Consequently, addressing traumatic stress within families in the child welfare system is essential for reducing rates of child maltreatment and interrupting the intergenerational transmission of trauma. Further, recognition of these risks can position attorneys to recommend resources to clients that lessen the impact of risks and bolster clients' resiliency.

Trauma can affect a parent's approach to discipline and child-rearing.

Parents with trauma histories who abuse or neglect their children may view their parenting behavior as normal, and may not understand that there are alternative ways of interacting with their children. Additionally, a traumatized parent may be hypervigilant or overly focused on identifying potential threats to his or her child. Hypervigilant parents may react harshly to child misbehavior because they fear consequences or reactions from others if their children continue to misbehave. Parents with trauma histories may also place extreme restrictions on their children, such as requiring them to spend all free time at home to avoid potential danger. Trauma can also deplete a parent's psychological and physical energy as well as the financial and social resources necessary to accomplish parenting tasks.

After a client-centered decision-making process that includes legal counseling of the client, parent attorneys can advocate for participation in trauma-informed parenting workshops and treatment *(see Section Six)*. Since reunifi-

GLOSSARY OF TERMS

Trauma
Exposure to actual or threatened death, serious injury or violence in one of the following ways: 1) direct experience; 2) witnessing a traumatic event; 3) learning that a loved one experienced trauma; or 4) repeated or extreme exposure to aversive details of traumatic events (e.g., child welfare attorneys who develop secondary traumatic stress after repeated exposure to their clients' trauma stories).

Child Traumatic Stress
Occurs when a child experiences a traumatic event or situation that upsets and overwhelms his or her ability to cope; and the signs and symptoms interfere with the child's daily life.

The Body's Alarm System
Function of the brain that scans the environment for potential danger and prepares us to act. When triggered, the alarm system sets off a cascade of immediate physiological changes that prepare one for Fight-Flight-Freeze response in order to stay safe. This is a complex response that involves multiple areas of the brain, including the sympathetic nervous system and the amygdala.

Trigger
A reminder of a past traumatic event that sets off the body's alarm system, so that the person feels in imminent danger once again. A "trigger" can be anything connected to a traumatic event, including an event, situation, place, physical sensation, or even a person.

Posttraumatic Stress Disorder
A mental health disorder most commonly associated with trauma exposure. PTSD is characterized by problems in four areas: re-experiencing (i.e., flashbacks or nightmares of traumatic event); avoidance of thoughts or reminders of past trauma;

cation is the ultimate goal in most child welfare cases, and most children in the child welfare system reunify with their biological families[17], it is essential that parents and caregivers receive needed trauma-informed services in order to begin the healing process and improve their capacity to provide safe and stable home environments.

Trauma can affect parental reactions to court proceedings and an attorney's working relationship with the parent.

For parents or caregivers with histories of trauma, child welfare proceedings may present particular challenges that can significantly interfere with their ability to effectively manage court proceedings and relationships with court and child welfare professionals. Parents who have experienced trauma may exhibit difficult behaviors such as angry outbursts, lateness, refusal to return phone calls, and missed appointments or court appearances. One study of child welfare-involved mothers also found that those who had previous involvement with the system as children were significantly less engaged with services provided through child welfare agencies.[18] These behaviors may be interpreted as hostility or apathy, but may in fact be symptoms of traumatic stress. Traumatic stress pushes the brain into a hypervigilant mode that may cause individuals to be highly sensitive to power differentials, perceived attacks, and a perceived loss of control. This may result in a parent's distrust of, and irritability toward, those who appear more powerful and in control, such as attorneys, judges, and child welfare caseworkers.[a] In such cases, parents may need additional support to help them understand those reactions, and the impact of those reactions on the overall case. Lifelong traumas may also teach ineffective ways to assert power in the world. It is understandable for parents to exhibit distrust of a system that may have been unhelpful, even harmful, in the past, especially if they have lived in poverty and have dealt with structural racism in the very systems designed to help them. Understanding these reactions can help you develop a more effective attorney-client relationship.

[a]*Traumatic stress may decrease a parent's ability to perceive the world accurately, process information, remain organized due to executive function deficits, and increase risk of substance use. In turn, this may contribute to an increased risk of maltreating their children.*

negative changes in thought or mood (i.e., persistent negative emotions, persistent or exaggerated negative beliefs about oneself, others, or the world); and hyperarousal (angry outbursts, being constantly "on guard" against potential threats). Some people may also experience dissociation. (See Appendix Section Two for additional information).

Complex Trauma
Refers to exposure to multiple or prolonged forms of traumatic experiences in childhood and the wide-ranging, long-term impact of this exposure. Complex trauma disrupts normal child development and may lead to difficulties with attachment (i.e., ability to form trusting, meaningful relationships); managing emotions and behavior; and executive functioning (i.e., ability to focus attention, solve problems, plan or pursue long-term goals).

Kinship Foster Care
Refers to the placement of youth in foster care that is provided by grandparents, aunts, uncles, or other family members.

Fictive Kin
Individuals who play an important role in a youth's life but are not related through marriage or birth.

Dual-System Involved Youth
Refers to youth who are involved in both the child welfare and juvenile justice systems.

Psychological Safety
The belief that one is safe from emotional harm and has the ability to manage threats to safety. Psychologically safe environments encourage respect for others' feelings, even when there is disagreement. Individuals can also increase their own sense of psychological safety in stressful situations by learning and using coping skills.

Dual-System Involved Youth
Youth involved in both the child welfare and juvenile justice systems)

4 The Impact of Trauma on the Attorney-Client Relationship

Trauma can interfere with the formation of strong client-attorney relationships by impairing the client's capacity to trust others, process information, communicate, and respond to stressful situations. Understanding trauma's impact on behavior can help you modify your approach with traumatized clients, prepare clients for court proceedings in a way that reduces their likelihood of a traumatic response, and advocate for clients in a way that empowers them and helps build a sense of safety and resiliency. With adequate preparation, clients may feel empowered by the opportunity to tell their stories and receive empathy and effective support from the professionals involved.

To establish an effective working relationship with traumatized clients, you should focus on physical and psychological safety, communication, and client support.

Physical and psychological safety:

When a client is reminded, either consciously or unconsciously, of a past trauma, that trigger may cause the client to feel as if she is in imminent danger. When traumatized clients feel physically or psychologically unsafe, they may become focused on protecting themselves and avoiding the perceived danger. As a result, they may not listen to or process information accurately, may refuse to talk, or simply agree to anything in order to leave. You can assist your client and establish a safe environment by providing structure and predictability, allowing the client to make informed decisions about his or her case whenever possible.

Court hearings and other procedures in the child welfare system may inadvertently trigger or re-traumatize clients with trauma histories. For example, clients are frequently triggered by a perceived loss of control or power, such as court decisions made about placement or visitation. Therefore, you should give clients a clear voice in decisions related to their representation, elicit their views, and seek active, age-appropriate involvement.

When triggered, clients may react in ways that are misinterpreted by the court. For example, a child may withdraw emotionally or physically *(often described as freezing or shutting down)* in response to questions about desire for contact with a parent. Or, a parent with a trauma history may shut down or react defiantly during cross-examination. A child placed in foster care, particularly an adolescent, may run away or act out in response to conflict with a foster parent or group home staff member. Judges, attorneys, and other professionals may view such a client as uncooperative or disinterested rather than as someone who is having a trauma response. You can advocate for clients by explaining to the court and the other parties that the client's behavior is a reflection of underlying trauma. Decisions regarding such disclosures should be case-specific and within the bounds of attorney-client privilege and your specific attorney role.

Some suggestions for increasing physical and psychological safety include:

- Meet in a quiet space where there are minimal distractions, away from other parties who may make your client feel threatened.
- Inform the client of the purpose of that day's meeting, what to expect during the meeting, and how long the meeting will last. Several shorter meetings can build familiarity and be more productive than a single, longer meeting. Make sure to ask what questions the client may have.
- Explain the court process. Let the client know what you are going to say in court, questions you may ask the client, and questions the judge or opposing attorney may ask (particularly when you anticipate an adversarial cross-examination). Knowing what to expect can help your client feel less anxious during a hearing. Allowing the client time to practice responding and role-playing can increase a sense of control and safety.

As part of explaining the court process to child clients, it is also important to provide a realistic understanding of the potential outcomes of a court hearing. It can be empowering for child clients to know that their attorney is listening to them and will express their wishes in court, but it is also important for them to be prepared for the possibility that those wishes may or may not be granted or taken into consideration.

Additionally, when child clients are not present for court hearings, it can be triggering for them to know there was a court date but not be informed about what happened at that hearing. Children and youth should attend their own hearings whenever possible. When their presence is not possible, it is important to provide information about what happened or some type of update in an age-appropriate manner.

Communication:

Clients who have experienced trauma may experience greater difficulty forming trusting relationships with their attorneys. Many youth in the child welfare system have been hurt by a caretaker or authority figure they trusted, and many parents distrust "the system." Such clients may not believe that you will actually advocate for them. Clients also may be slow to share emotionally-charged information, or may not feel safe expressing preferences regarding their desired outcomes, such as visitation or placement. Developing an effective attorney-client relationship takes time and patience.

You can learn to recognize signs that a client may be experiencing a trauma reaction so that you do not misinterpret or exacerbate the client's response. Trauma reactions typically represent some version of fight, flight, or freeze. A client who suddenly becomes loud or combative may be going into "fight mode" in order to keep herself safe by pushing others away. Clients may go into "flight mode" and try to avoid a triggering situation by refusing to answer sensitive questions or attempting to leave a meeting or court hearing. Clients may also "freeze" by shutting down or dissociating *(a common response to trauma when a person mentally shuts down or "goes elsewhere")*. She may sit quietly but will no longer be paying attention. Do not assume that silence means the client understands or consents. *(Appendix Section Four includes information about identifying signs of trauma reactions in clients.)*

PRACTICE TIPS TO AVOID TRIGGERING CLIENTS WITH PRIOR TRAUMA

Look for signs of trauma reactions. As discussed in this section, clients may exhibit variations of the fight, flight, or freeze response.

Try not to startle the client. Loud noises *(including yelling)*, sudden movements *(jumping up from a chair)*, or unexpected news can all trigger trauma responses.

Prepare the client for what is ahead. Predictability is important to establishing a trusting relationship. Preparation can help minimize your client's hypervigilance to threats from unfamiliar or unexpected sources.

Minimize touching the client. You may intend to be supportive when you put your arm around a child or touch a parent's shoulder, but that can trigger a reaction in people who have been physically or sexually abused. By respecting your client's personal space, you can help build the client's sense of control and safety.

Do not overpromise or tell the client "everything will be fine." This includes promising clients you will always be there for them. Attorneys frequently change. Be honest in your communications because clients may be triggered by feeling let down or misled by their attorney. Remember that clients' behaviors may also be influenced by the expectation that you will inevitably disappoint them, so be honest and forthright from the start.

[b] *Child participation in the court process is considered a best practice by national organizations such as the American Bar Association, National Council of Juvenile and Family Court Judges, and National Association of Counsel for Children. A study in Nebraska found that children's anxiety levels related to court participation were low overall and even lower for children who had attended court. The children who attended court also viewed the judgments as more fair. A recent New Jersey study showed that court participation is not upsetting for youth, but can provide an opportunity for them to be heard. It also provides better information to both the youth and the court.*[19]

Client support:

Parents and children who are involved in the child welfare system may still have strong attachments to and pleasant memories of family members. In fact, a child can remain emotionally attached to a dysfunctional family and may be further traumatized by complete loss of contact with relatives. Family members can offer the best source of long-term support for a traumatized child. It is essential that a child stay connected with siblings, relatives and extended family (as defined by the client), and friends. In cases in which ongoing family contact is not feasible or is contraindicated for safety reasons, you can look for ways to involve other people trusted by your client, such as a family friend, coach, teacher, or pastor.

Finally, you should be aware that some clients may find the experience of court involvement traumatizing, whether from memories of past involvement, interactions with or observations of others in the courthouse, and especially the intensity of the courtroom environment itself. Trauma triggers might include an attorney's behaviors, tone of voice, body language or approach to questioning. You can take steps to make your clients more comfortable and to recognize when clients are having a trauma reaction.

POSSIBLE SIGNS THAT YOUR CLIENT HAS BEEN "TRIGGERED"

- Lashes out verbally or physically
- Becomes defiant, disrespectful
  (fight response meant to keep potential threats at a distance)
- Has difficulty tracking the attorney's questions
- Shuts down, stops talking
- Becomes jumpy, fidgety, starts pacing
- Has sudden, dramatic shifts in mood
- Looks spaced out, gets lost in conversation, or appears to have "gone somewhere else"
- Speech grows louder, faster
- Suddenly tries to leave situation
  (flight response)
- Adopts regressive behaviors
  (thumb sucking, rocking)

Client Resiliency:

It should be noted that despite trauma histories and traumatic stress reactions, clients are often resilient. Your actions during the course of legal proceedings can further bolster resiliency. Whether through advocacy for treatment *(Section Six: Effective Treatments for Traumatic Stress)* or facilitating a client-attorney relationship that conveys awareness of traumatic stress reactions, promoting a psychologically safe environment using the above strategies can support your clients' improved management of traumatic stress reactions.

5 Screening and Assessment

Clients involved in child welfare proceedings should be routinely screened for exposure to trauma and related mental health conditions in order to determine their need for therapy and other services. In this section we distinguish between screening, assessment, and neuropsychological evaluations.

Screening refers to a brief set of questions administered to children, parents or caregivers to identify clients who likely suffer from trauma-related impairment. Screening can be conducted by attorneys using validated assessment instruments. Any client who screens positive for likely trauma exposure or symptoms can be referred to a qualified mental health professional for a full assessment. Various trauma-informed screening instruments and questionnaires are available for use *(see NCTSN Measures Review Database)*.[20]

A ***trauma-informed mental health assessment*** refers to a comprehensive evaluation conducted by a trained mental health provider such as a social worker, psychologist, or psychiatrist. The goal is to determine if the client is suffering from traumatic stress or other mental health problems and to generate recommendations for treatment or other social services. The provider conducting the assessment gathers information on trauma experiences or symptoms along with other mental health symptoms, medical issues, academic and employment history, and family dynamics, as well as strengths exhibited by the child, parent, family, and community. A thorough assessment should include information from several sources, including clinical interviews with the child, caregivers, and collateral informants; review of client records (school, medical, and mental health treatment); and behavioral observations.

Neuropsychological evaluation *(also referred to as cognitive evaluation)* is used to assess a child's current level of intellectual and academic functioning. Such evaluations may be warranted for clients who are experiencing significant academic or vocational problems or are suspected of having undiagnosed learning disorders or developmental delays. The latter are quite common among children with prior trauma exposure. You may need to make the case that such an assessment is required by reasonable efforts and request that the court order the assessment and approve payment by the child welfare agency.

Integrating trauma screening and assessment findings into court reports is a key element of a trauma-informed child welfare court system. Including these findings will assist the court to understand the impact of trauma on the child and parent, develop plans that support their resilience, and avoid decisions that may re-traumatize the child and parent. Screenings, assessments, and evaluations may need to be court-ordered. Depending on local law, the results are generally made available to all parties or may be obtained by one party or the other for use as an advocacy tool.

PRACTICE TIPS: CONSIDERATIONS FOR TRAUMA SCREENING AND ASSESSMENT

A trauma assessment is very different from a mental health assessment conducted as part of a custody evaluation. The former is not designed to provide recommendations regarding placement and visitation within the child welfare context.

Although it is recommended that you advocate for trauma-informed assessments of clients who screen positive for trauma exposure or symptoms, this may not always be possible within the confines of your particular role. Parents' attorneys in particular may resist trauma assessments if the parent client is not amenable to an assessment or if the attorney has concern that the parent may be viewed by courts as too "damaged" to be rehabilitated. In this case, one option is to consider whether this concern is outweighed by the potential benefits. Trauma screening and assessment will help ensure that parents with traumatic stress receive appropriate services to help facilitate their healing and address mental health issues that potentially impact their legal cases. While it is ultimately the client's decision, parents' attorneys can also engage in client-centered counseling to present both the potential benefits and potential risks of a trauma-informed assessment.

You should be aware of potential legal consequences related to information shared during court-ordered assessments. For example, an accused parent may report information on trauma history that could be used against him in court proceedings. Likewise, acknowledgment of living with an abusive spouse could be used as evidence that the parent is providing an unfit home environment for the child.

Whenever possible, each child and parent involved in child welfare proceedings should be screened for traumatic events and related symptoms as long as the jurisdiction has sufficient legal protections to ensure the information will not be used in ways that will further harm the youth or family.

Not all mental health agencies routinely ask about trauma exposure or symptoms during their assessments. You should make efforts to ensure that the child welfare agency arranges for trauma-informed assessments.

6 Effective Treatments for Traumatic Stress

Even severely traumatized youth and adults can recover from trauma with the right supports, including effective mental health treatment. The terms trauma-informed or trauma-focused treatment refer to mental health interventions designed to help people recover from traumatic stress. There are evidence-based trauma-informed or -focused interventions for every age group, ranging from infants to adults *(see NCTSN Empirically Supported Treatments and Promising Practices)*.[21]

There are individual treatments for a traumatized child or parent as well as treatments designed for the parent and child to work together. Trauma-focused treatments can support client resilience by helping the client develop effective coping and problem-solving skills, build on strengths, reduce trauma-related symptoms, and improve social, academic, and developmental functioning. Trauma-informed treatment has been shown to improve mental health and behavioral outcomes among children and parents and to reduce the likelihood of future abuse or neglect.[22, 23]

Whenever a client undergoes a comprehensive assessment *(see Section Five)* and is found to suffer from trauma-related impairment, you should advocate for trauma-informed treatment. A core principle of trauma-informed practice is to provide clients with a sense of control over the process. Thus, you should ask about and advocate for client preferences about treatment modality *(e.g., individual, family, or group treatment)* and therapist gender. Regarding the latter, some youth have an aversion to or may be triggered by a clinician of the same gender as their abuser.

Not all treatments are trauma-informed, including many of the treatments commonly recommended in family courts, such as parenting groups, substance abuse treatment, or anger management. Clients with traumatic stress are less likely to benefit from such interventions and more likely to end treatment prematurely. A negative treatment outcome may be used against the client (particularly a parent) as evidence he is unwilling or too damaged to change behaviors. Therefore, you should advocate that your clients are referred to trauma-informed treatment when indicated.

Many mental health providers have not been trained in trauma-informed treatment. In order to identify trained providers, you can search through relevant online directories. You can also interview prospective treatment providers to determine whether they offer trauma-informed treatment *(see Appendix Section Six)*.

CORE ELEMENTS OF TRAUMA-INFORMED/FOCUSED TREATMENT

- Educating clients regarding trauma and its impact
- Increasing client sense of physical & psychological safety
- Identifying triggers for trauma reactions
- Developing emotional regulation skills
  (i.e., skills to help control and express strong feelings)
- Developing trauma-informed parenting skills
- Addressing grief and loss *(when appropriate)*
- Processing traumatic memories

7 Placement Decisions, Transitions, and Visitation

The child welfare court system has historically focused on physical safety. More recently, however, there has been increased attention on ensuring psychological safety for children and families. Psychological safety is the ability to feel safe within one's self as well as safe from external harm. The inability to feel safe can impact an individual's interactions with others, can lead to a variety of maladaptive coping strategies, and can result in anxiety.

Removing a child from a home where there is neglect or abuse may improve his or her physical safety, but at the same time may impair the sense of psychological safety for both the child and the parents. Research shows that frequent placement changes are associated with poor outcomes for children involved in the child welfare system.[24,25] You may not have the power to alleviate your clients' distress, but you can minimize trauma caused to families involved in the child welfare system and improve their sense of safety by becoming an advocate for them during the following critical junctures:

Placement Decisions:

In jurisdictions with client-directed representation, you should advocate for a child client's stated interests. Giving a child a voice in the proceedings will help the child feel that she has some control in a process that can otherwise be overwhelming and even traumatic. Attorneys advocating for the child's best interest should also consider the child's wishes in making the best-interest determination. You should first consider whether the child can safely remain in the home with any needed supports to minimize disruptions. When children must be removed from their homes, you should advocate that they be placed with a relative who is willing and able to provide a physically and psychologically safe home environment.

You should seek the input of your client, whether this is a child or parent, regarding relatives who may be able to provide a safe home for the child. You should also advocate for siblings to be placed together except in cases of suspected sibling abuse or other safety concerns. Research shows that youth who are initially placed in kinship foster care and with all their siblings are significantly more likely to achieve stable placement and exit the system.[26]

In cases when an out-of-home placement is unavoidable, you should consider advocating for a placement close to the child's home community. This will allow the child to maintain connections with his or her support systems including extended family, church, school, teachers, mentors, and coaches. When a child is placed outside his community, you should advocate that he remain in the same school, unless it is in his best interest to move to a new school. This can also provide the stability, continuity, and connections with adults that are needed. One positive relationship with an adult can make all the difference for a child! Having a stable, nurturing relationship with an adult can facilitate tremendous healing and develop resilience for a child who has experienced trauma.

Transitions:

You can help with transitions through thoughtful and planned decisions regarding placements, visitation, and reunification. You can:

- Advocate for a minimal number of moves and placement changes
- Assess the appropriateness of any placement based on the child's emotional, social, developmental, and medical needs
- Advocate for allowing both the child and caregiver time to prepare for visits with a parent
- Request time to say goodbye to a foster family by planning for reunification or a placement change in advance.

Visitation:

Children involved in the child welfare system often strongly voice a desire for contact with their parent(s), even in cases when the parent was abusive or neglectful. Thus, attorneys representing children or parents should advocate for visitation to begin as soon as possible except when it threatens the physical or psychological safety of the child or the child expressly does not want visitation with a parent.

Visitation should be intentional and well planned. It should be held in a neutral location away from any environment where a child may have experienced trauma. When appropriate, encourage and facilitate positive relationships and communication between birth parents and caregivers about the child's routines, habits, triggers, and coping skills. *(See Appendix Section Seven: "Working with Parents Involved in the Child Welfare System – Visitation.")*

Visits may trigger trauma reactions, so you can prepare your client *(child or parent)* in advance. It may be beneficial to communicate with the client's therapist to understand potential reactions to visits or when considering advocating for a change in visitation. Ask child clients how they feel about visits and try to determine what might trigger them *(sights, sounds, smells, places, voices, etc.)*. You should communicate with the therapist regarding a client's reactions to visits before requesting changes in visitation. You can also encourage parent clients to use visits as an opportunity to practice certain skills and demonstrate their ability to parent safely.

8 Secondary Traumatic Stress and Attorneys

The terms vicarious trauma or secondary traumatic stress *(STS)* describe the negative physical and psychological health consequences resulting from repeated exposure to the stories and experiences of traumatized clients. Attorneys handling child welfare cases are at high risk for developing secondary traumatic stress reactions due to frequent exposure to trauma survivors and their stories of maltreatment. Furthermore, research suggests that a substantial number of attorneys, particularly attorneys practicing specialties such as criminal law and family law, will be threatened with violence at least once in their careers.[27] One study of public defenders found that 34 percent of attorneys reported symptoms of STS while 11 percent met criteria for a diagnosis of PTSD.[28,29]

STS reactions range from decreased empathy towards clients and changes in a sense of personal safety to the onset of PTSD symptoms *(see Section Two)*. STS can lead to impairment in your mental or physical health, job performance, and personal relationships.[30] Those affected by STS may engage in risky or unhealthy behaviors to cope with STS. These behaviors may include increased substance use, experiencing feelings of estrangement from loved ones, or being overly focused on protecting one's own children from danger.

Risk Factors for Secondary Traumatic Stress:

Both individual and job-related or organizational factors may increase your risk for developing STS. Individual factors include a prior history of trauma exposure, such as attorneys who were themselves abused as children, and unhealthy strategies for coping with distress.[29] Job and organizational factors that influence risk for STS include the number of trauma survivors in your caseload, level of coworker and supervisor support, and education and training about STS.[31] In a study on the incidence of STS among attorneys, participants attributed their traumatic stress reactions to a lack of education about understanding clients with trauma histories and the absence of a regular forum for discussing the stress of working with such clients.[32]

Preventing Secondary Traumatic Stress:

There are several strategies that individual attorneys and agencies can adopt to help prevent STS. Training on working with trauma survivors has been shown to increase empathy and confidence in working with this population among mental health providers.[33] Recommended areas of focus for training with attorneys include:[31]

- Understanding the impact of trauma on children and adults
- Acquiring skills for working with trauma survivors
- Recognizing the signs and risks for secondary trauma and
- Practicing stress reduction and management skills such as mindfulness techniques

Formal supervision and peer support groups can also help prevent STS by providing support and a forum for discussing the challenges of working with trauma survivors. Agencies should also offer employee assistance programs or referrals to outside mental health providers for attorneys who develop symptoms of STS.

STRATEGIES FOR SELF-CARE

- Exercise regularly and maintain a consistent sleep schedule
- Eat healthy food and reward yourself with your favorite food occasionally
- Build breaks into your schedule—even if just a few minutes
- Connect daily with others who recharge your emotional state
- Practice mindful activities that can include meditation, yoga, or spiritual practices
- Set and maintain boundaries with clients: clarify that your role as attorney differs from those of social workers, case managers, or other service providers
- Reduce your caseload or diversify your practice, if possible
- Monitor your risk for STS by periodically completing a STS self-assessment tool such as the ProQOL or the Secondary Traumatic Stress Scale (see Appendix Section Eight for links)
- Connect clients with appropriate service providers—use a team approach for clients who have experienced trauma and need a high level of support
- Create a go-to list of local resources for clients
- Access state bar legal assistance programs or confidential support services when available or seek counseling services as needed

SIGNS OF VICARIOUS OR SECONDARY TRAUMATIC STRESS

- Disruption in perceptions of safety, trust, and independence
- Sleeping difficulties or nightmares
- Exhaustion
- Alcohol or drug use to self-medicate
- Anger or cynicism towards “the system”
- Difficulty controlling emotions
- Hyper-sensitivity to danger
- Increased fear and anxiety
- Intrusive thoughts or images of client trauma stories
- Social withdrawal
- Minimizing the impact of trauma
- Illness, increase in sick days at work
- Diminished self-care and depletion of personal resources
- Reduced sense of self-efficacy

POTENTIAL IMPACT OF SECONDARY TRAUMATIC STRESS ON JOB PERFORMANCE

- Reduced empathy towards clients
- Inability to listen to, or active avoidance of, clients
- Over-identification with clients, or conversely, shutting down emotionally *(both responses interfere with effective legal representation)*
- Distancing oneself from exposure to key aspects of a client's history and ongoing trauma, thereby potentially missing events with high probative value in litigation
- Overreaction by displaying hypervigilance through angry outbursts in court, or unduly questioning the credibility of witnesses when emotional legal issues become triggers
- Excessive anger or irritability, as a result of STS, may be masked as zealous advocacy in a trial setting, but may in fact be damaging to the attorney and client.
- Compromised quality of legal service due to emotional depletion or cognitive effects of STS. Some traumatized professionals, believing they can no longer be of service to their clients, end up leaving their jobs or the serving field altogether. Several studies indicate that the development of secondary traumatic stress often predicts that a helping professional will eventually leave the field for another type of work.

9 The Importance of Collaboration

Collaboration and coordination among service providers and systems comprise a key principle of trauma-informed practice.[5] Therefore, it is important for attorneys and other providers working on a case to both collect and share information to support their clients as appropriate within legal and ethical confines. Benefits of information-sharing include:

- Preventing clients from having to repeat their trauma histories to multiple agencies or providers
- Ensuring that all involved parties understand trauma's impact on the client and tailor their services accordingly
- Increased ability to make sense of the client's behaviors or difficulties

The following section lists the roles played by professionals most often involved in child welfare cases, their scope of practice, and recommendations regarding how to work with each.

Children's Attorneys and Guardians ad Litem:

Many children do not immediately disclose traumatic events, like sexual abuse. Such children are frequently misdiagnosed, based on their behavior, with emotional disturbance, oppositional defiance, bipolar disorder, attention deficit hyperactivity disorder *(ADHD)* or other physical or developmental disabilities. Children may not understand why they engage in these behaviors, and may be afraid to tell the truth because it would require disclosure of the trauma. Collaboration with other parties is key to determining whether another assessment might be warranted. Foster parents and other caregivers often have a wealth of information that can be helpful. Has the child experienced known or suspected abuse or other trauma? If the child is engaging in conduct at home, could that conduct be caused by neurological responses to trauma? Unprovoked anger may be a manifestation of the fight response; running out of school or from home, the flight response; and tuning out, the freeze response. Sleep disturbances *(losing sleep at night, and sleeping during the day)*, inability to focus, and depression may all be caused by trauma. Are there situations that trigger these behaviors? Does the child engage in self-harm, or appear depressed? What helps the child calm down? Conducting a thorough and independent investigation by collecting information from others can help you better understand the child's situation.

Sharing information *(as allowed under ethics rules and privacy statutes)* with parent attorneys, the treating therapist, school personnel, and court staff may benefit the child as well.

Parent Attorneys:

Parents may also have information that can help. However, there are important considerations related to confidentiality and other barriers that a parent attorney must consider. When it can benefit the parent and facilitate help for the child, a parent's attorney can encourage the parent to consider sharing this information. Parent attorneys can also ask their clients about how trauma may affect their parenting ability and discuss with their client the benefits and drawbacks of sharing this information.

Child Welfare Agency Case Worker:

Child services workers are required to regularly check on the child. They see children interact with their parents, foster parents, or kinship caregivers, often in the home. Much of the information case workers discover is incorporated into case planning and reports to the court. They often have additional information that may shed light on the child's experiences.[34,35,36]

School Personnel:

Knowledge and incorporation of trauma-informed practices varies widely among different school systems. It is important that providers involved with the child's case, after obtaining the appropriate releases, inform the school about the child's special trauma needs. A child's case file will often contain information about the child's history, experiences, and family background that the school does not need in order to provide services. However, not all schools have comprehensive policies to protect children's privacy. You should ensure that only the information needed to serve the child is provided to the school, and that such information is provided only to individuals who have been trained to ensure and protect the child's confidentiality.

Many children who are experiencing neurological responses to trauma require accommodations in school to access their education. Common accommodations often provided in an Individual Education Plan *(IEP)* or 504 plan, include:

- Permitting the child to leave class early *(to avoid the hustle and bustle of busy pass times in the hall)*
- Permitting the child to leave class at any time to speak to a counselor
- Providing trigger warnings of materials in the curriculum that might trigger the student, and furnishing alternative assignments *(for example, doing an independent study in English when the class is studying a book that will likely trigger the student)*
- Adjusting the child's class schedule so the child can sleep later in the morning

The school may also have information that will help with understanding the child's needs. For this reason, ongoing dialogue with the school is essential.

Court staff:

Children's attorneys should take the lead to make sure that the child's needs are met in court and that court staff are aware of potential concerns. Important questions to consider include: Will the child or caregiver need accommodations in court? Will the client be triggered if the abuser *(i.e., abusive parent or partner)* will be in the courtroom? Do special arrangements need to be made?

Treating therapist:

With regular collaboration, the treating therapist can play a key role in making sure that a client's needs are met at school, at home, and in court. Attorneys and therapists alike must be mindful of their respective ethical duties to their clients. Treating therapists can generally opine about a client's needs and what would be helpful without violating client confidentiality. You should advise the therapist of upcoming court hearings so the therapist can help the client process the information, address potential triggers, and prepare for court. It is also helpful to obtain information from the treating therapist about a client's potential trauma triggers and strategies for preventing, addressing, or mitigating those triggers. Likewise, if a client is at risk for self-harm, you should speak to the therapist and inquire about steps or strategies that have been discussed with the client or put into place to reduce this risk.

10 Systems-Level Advocacy and Resources

The current guide was developed with two goals. The first goal is to increase the knowledge and skills of individual attorneys who work with clients who have survived trauma. The second, broader goal is to create trauma-informed child welfare and family court systems, in which all professionals, consumers, and stakeholders are educated about the impact of trauma and trauma-informed practices and policies. Creating trauma-informed service systems is a time- and resource-intensive effort that will require the involvement of a variety of stakeholders in child welfare and other service systems. In the list below, we have included specific resources that may assist attorneys and other system stakeholders in beginning to implement trauma-informed care in their local child welfare and family court systems. The Appendix to this document also includes additional resources to assist attorneys in both individual and systems-wide advocacy and practice.

Resources for educating other stakeholders on trauma-informed care

American Bar Association Center on Children and the Law's website on *Polyvictimization and Trauma-informed Legal Advocacy* http://www.americanbar.org/groups/child_law/what_we_do/projects/child-and-adolescent-health/polyvictimization.html

National Child Traumatic Stress Network and National Council of Juvenile & Family Court Judges. (2013). *Bench card for the trauma-informed judge*. Los Angeles, CA and Durham, NC: Authors. http://www.nctsn.org/products/nctsn-bench-card-trauma-informed-judge

National Child Traumatic Stress Network (2005). *Helping children in the child welfare system heal from trauma: A systems integration approach.* http://www.trauma-informed-california.org/wp-content/uploads/2012/02/A_Systems_Integration_Approach.pdf

National Council of Juvenile & Family Court Judges (2014). *Trauma court audit*. http://www.ncjfcj.org/sites/default/files/Trauma%20Audit%20-%20Snapshot.pdf

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APPENDIX

Section One: Defining Trauma-Informed Legal Advocacy

American Bar Association's Policy on Trauma-Informed Advocacy for Children and Youth (2014) http://www.americanbar.org/content/dam/aba/administrative/child_law/ABA%20Policy%20on%20Trauma-Informed%20Advocacy.authcheckdam.pdf

National Council of Juvenile & Family Court Judges (NCJFCJ) site on Trauma-Informed Systems of Care http://www.ncjfcj.org/our-work/trauma-informed-system-care

Section Two: The Impact of Trauma Exposure on Child Development

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Section Three: The Impact of Trauma Exposure on Parents

NCTSN Fact Sheet: *Birth Parents with Trauma Histories and the Child Welfare System*
This factsheet series from the Birth Parent Subcommittee of the Child Welfare Committee highlights the importance of understanding the serious consequences that trauma histories can have for birth parents and the subsequent potential impact on their parenting.

- For Parents (2012)
- For Child Welfare Staff (2011)
- For Judges and Attorneys (2011)
- For Mental Health Professionals (2012)
- For Resource Parents (2011)
- For Court-Based Child Advocates and Guardians ad Litem (2013)

Section Four: The Impact of Trauma on the Attorney-Client Relationship

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Section Five: Screening and Assessment

Vandervort, F. E. (2015). Using screening and assessment evidence of trauma in child welfare cases. *Child Law Practice, 34.* Available from http://www.americanbar.org/publications/child_law_practice/vol-34/may-2015/using-screening-and-assessment-evidence-of-trauma-in-child-welfa.html

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Section Six: Effective Treatments for Traumatic Stress

Finding Effective Trauma-Informed Treatment for Children, Teens, & Families
http://www.nctsn.org/resources/topics/treatments-that-work/promising-practices
The National Child Traumatic Stress Network's website includes a comprehensive list of the most effective and widely used trauma-informed treatments for children, adolescents, and families. This site includes a description of the core components of trauma-informed treatments and a list of trauma-informed interventions for children, adolescents, and families, with fact sheets summarizing the key components of each treatment and the research evidence that shows its effectiveness.

Finding a Trauma-Informed Therapist or Expert in Your Area
http://www.nctsn.org/about-us/network-members
The National Child Traumatic Stress Network is comprised of more than 100 federally-funded and affiliated academic and treatment centers around the US that provide trauma-informed mental health services and training/consultation on child traumatic stress. To find a trauma expert in your area, search the NCTSN's list of network members by state

http://www.istss.org/find-a-clinician.aspx
The International Society for Traumatic Stress Studies offers a searchable online database of mental health professionals that offer trauma-informed treatment across the globe.

http://www.nctsn.org/resources/get-help-now
The NCTSN's *Get Help Now* site offers information on finding help for children who have experienced abuse or neglect.

NCTSN Fact Sheet: *List of Questions to Ask Mental Health Professionals*

1. Does the individual/agency that provides therapy conduct a comprehensive trauma assessment?
   If so: What specific standardized measures are given? What did your assessment show? What were some of the major strengths and/or areas of concern?
2. Is the clinician/agency familiar with evidenced-based treatment models?
3. Have clinicians had specific training in an evidenced-based model *(when, where, by whom, how much)*?
4. Does the individual/agency provide ongoing clinical supervision and consultation to its staff, including how model fidelity is monitored?
5. Which approach(es) does the clinician/agency use with children and families?
6. How are parent support, conjoint therapy, parent training, and/or psychoeducation offered?
7. Which techniques are used for assisting with the following: Building a strong therapeutic relationship; affect expression and regulation skills; anxiety management; relaxation skills; cognitive processing/reframing; construction of a coherent trauma narrative; strategies that allow exposure to traumatic memories and feelings in tolerable doses so that they can be mastered and integrated into the child's experience; personal safety/empowerment activities; resiliency and closure
8. How are cultural competency and special needs issues addressed?
9. Is the clinician or agency willing to participate in the multidisciplinary team *(MDT)* meetings and in the court process, as appropriate?

Section Seven: Placement Decisions, Transitions, and Visitation

ReMoved – video about the experience of children in foster care system http://vimeo.com/73172036

NCTSN Presentation: *Working with Parents Involved in the Child Welfare System - Visitation*
http://www.nctsn.org/nctsn_assets/anc16_new/visitation/presentation_html5.html

ACS-NYU Children's Trauma Institute. (2012). *Easing foster care placement: A practice brief.* New York: NYU Langone Medical Center. Available from http://www.nctsn.org/sites/default/files/assets/pdfs/easing_foster_care_placement_practice_brief.pdf

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Section Eight: Secondary Traumatic Stress and Attorneys

Rainville, C. Understanding Secondary Trauma: A Guide for Lawyers Working with Child Victims, ABA Child Law Practice, Volume 34, Number 9 (September 2015). Available from http://www.americanbar.org/groups/child_law/what_we_do/projects/child-and-adolescent-health/polyvictimization/understanding-secondary-trauma--a-guide-for-lawyers-working-with.html

Institute for Redress & Recovery, Santa Clara Law. (n.d.) *Secondary trauma and the legal process: A primer & literature review*. Santa Clara, CA: Author. Available from http://law.scu.edu/redress#5

van Dernoot Lipsky, L., & Burk, C. (2009). *Trauma stewardship: An everyday guide to caring for self while caring for others*. San Francisco, CA: Berrett-Koehler Publishers. http://traumastewardship.com/inside-the-book/

The Professional Quality of Life Scale (ProQOL) is a 30 question assessment of secondary traumatic stress, burnout, and compassion satisfaction that is intended for use by a wide range of helping professionals. To download a free copy of the ProQOL, including instructions on how to complete and score the questionnaire, visit http://www.proqol.org/ProQol_Test.html. Mental health counseling or other supports can be helpful for addressing high scores on the secondary trauma or burnout scales of the ProQOL. Refer to Section 6 of this Appendix for additional information on locating a trauma-informed therapist in your area.

Section Nine: The Importance of Collaboration

Stewart, M. (2013). Cross-system collaboration. Los Angeles, CA & Durham, NC: National Center for Child Traumatic Stress. http://www.nctsn.org/sites/default/files/assets/pdfs/jj_trauma_brief_crosssystem_stewart_final.pdf

The Juvenile Law Center and Robert F. Kennedy National Resource Center for Juvenile Justice have developed the *Models for Change Information Sharing Toolkit*. Available from www.infosharetoolkit.org/

This project was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), US Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS. They have not been approved by the House of Delegates or the Board of Governors of the American Bar Association, and accordingly, should not be construed as representing the policy of the American Bar Association.

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What is Child Traumatic Stress?

What is child traumatic stress, how does it develop, and what are the symptoms? To answer these questions, we first have to understand what trauma is.

From a psychological perspective, trauma occurs when a child experiences an intense event that threatens or causes harm to his or her emotional and physical well-being.

Trauma can be the result of exposure to a natural disaster such as a hurricane or flood or to events such as war and terrorism. Witnessing or being the victim of violence, serious injury, or physical or sexual abuse can be traumatic. Accidents or medical procedures can result in trauma, too. Sadly, about one of every four children will experience a traumatic event before the age of 16.

When children have a traumatic experience, they react in both physiological and psychological ways. Their heart rate may increase, and they may begin to sweat, to feel agitated and hyperalert, to feel "butterflies" in their stomach, and to become emotionally upset. These reactions are distressing, but in fact they're normal — they're our bodies' way of protecting us and preparing us to confront danger. However, some children who have experienced a traumatic event will have longer lasting reactions that can interfere with their physical and emotional health.

Children who suffer from child traumatic stress are those children who have been exposed to one or more traumas over the course of their lives and develop reactions that persist and affect their daily lives after the traumatic events have ended. Traumatic reactions can include a variety of responses, including intense and ongoing emotional upset, depressive symptoms, anxiety, behavioral changes, difficulties with attention, academic difficulties, nightmares, physical symptoms such as difficulty sleeping and eating, and aches and pains, among others. Children who suffer from traumatic stress often have these types of symptoms when reminded in some way of the traumatic event. Although many of us may experience these reactions from time to time, when a child is experiencing child traumatic stress, they interfere with the child's daily life and ability to function and interact with others.

Although many of us may experience reactions to stress from time to time, when a child is experiencing child traumatic stress, these reactions interfere with his or her daily life and ability to function and interact with others.

Some of these children may develop ongoing symptoms that are diagnosed as post-traumatic stressdisorder (PTSD). When we talk about child traumatic stress, we're talking about the stress of anychild who's had a traumatic experience and is having difficulties moving forward with his or her life. When we talk about PTSD, we're talking about a disorder defined by the American Psychiatric Association as having specific symptoms: the child continues to re-experience the event through nightmares, flashbacks, or other

symptoms for more than a month after the original experience; the child has what we call avoidance or numbing symptoms—he or she won't think about the event, has memory lapses, or maybe feels numb in connection with the events—and the child has feelings of arousal, such as increased irritability, difficulty sleeping, or others. Every child diagnosed with PTSD is experiencing child traumatic stress, but not every child experiencing child traumatic stress has all the symptoms for a PTSD diagnosis.

And not every child who experiences a traumatic event will develop symptoms of child traumatic stress. Whether or not your child does depends on a range of factors. These include his or her history of previous trauma exposure, because children who have experienced prior traumas are more likely to develop symptoms after a recent event. They also include an individual child's mental and emotional strengths and weaknesses and what kind of support he or she has at home and elsewhere. In some instances, when two children encounter the same situation, one will develop ongoing difficulties and the other will not. Children are unique individuals, and it's unwise to make sweeping assumptions about whether they will or will not experience ongoing troubles following a traumatic event.

For children who do experience traumatic stress, there are a wide variety of potential consequences. In addition to causing the symptoms listed earlier, the experience can have a direct impact on the development of children's brains and bodies. Traumatic stress can interfere with children's ability to concentrate, learn, and perform in school. It can change how children view the world and their futures, and can lead to future employment problems. It can also take a tremendous toll on the entire family.

Not every child who experiences a traumatic event will develop symptoms of child traumatic stress. Whether or not your child does depends on a range of factors.

The way that traumatic stress appears will vary from child to child and will depend on the child's age and developmental level. The good news is that over the past decade the mental health community has developed treatments that can help children suffering from traumatic stress. It's important to seek help from someone who has experience working with children and knows how to access resources in your community.

Although not every child will experience traumatic stress, it's unlikely that any of us are immune from exposure to trauma. To learn more about child traumatic stress, please visit the National Child Traumatic Stress Network website at www.NCTSN.org.

This article first appeared in the fall 2003 issue of Claiming Children, the newsletter of the Federation of Families for Children's Mental Health, www.ffcmh.org, which was co-produced by the Federation and the NCTSN.

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

Disability Advocacy Conference
May 1, 2019

What's on the Way at the GA?

Table of Contents

- PowerPoint Presentation Handout

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

What's on the Way at the GA?
The 2019 Legislative Session and People with Disabilities

Disability Advocacy Conference – May 1, 2019

Corye Dunn, Director of Public Policy
Meisha Evans, Policy Analyst

The Legislative Calendar

- Part-time legislature
- Biennium
- Long session runs Late January to Summer?
- Full budget year

2

Medicaid Reform

- The train is moving
- Standard Plans 2019-20
- Tailored Plans to follow
- Four statewide plans, two regionals (same entity)
- Still big decisions to make about foster youth and others

3

Budget

- Two year budget begins July 1, 2019
- Governor's budget is out but unlikely to influence House or Senate versions

4

Rethinking Guardianship

- Study bill
- Based on four year workgroup
- Calls for report and recommendations on key findings of Rethinking Guardianship

5

And So Much More!

- School safety
- Raise the Age
- Criminal justice- Capital Procedures
- Education- Mental Health in Schools

- Whatever comes up!

6

How to keep up...

- www.ncleg.net calendars, audio, bill info and dashboard
- Facebook -- follow Disability Rights NC and others
- Twitter #ncpol, #ncga

7

Questions

8