

The background features abstract, flowing ribbons of color. A vibrant red ribbon curves from the bottom left towards the center, while a bright cyan ribbon flows from the top right towards the center. The background is primarily black, with a gradient of orange and yellow at the top edge.

COMMUNITY SERVICES FOR PERSONS WITH IDD*:

ADVOCACY, NEURODIVERSITY & SERVICE ENVIRONMENTS

QUICK NOTE ON LANGUAGE

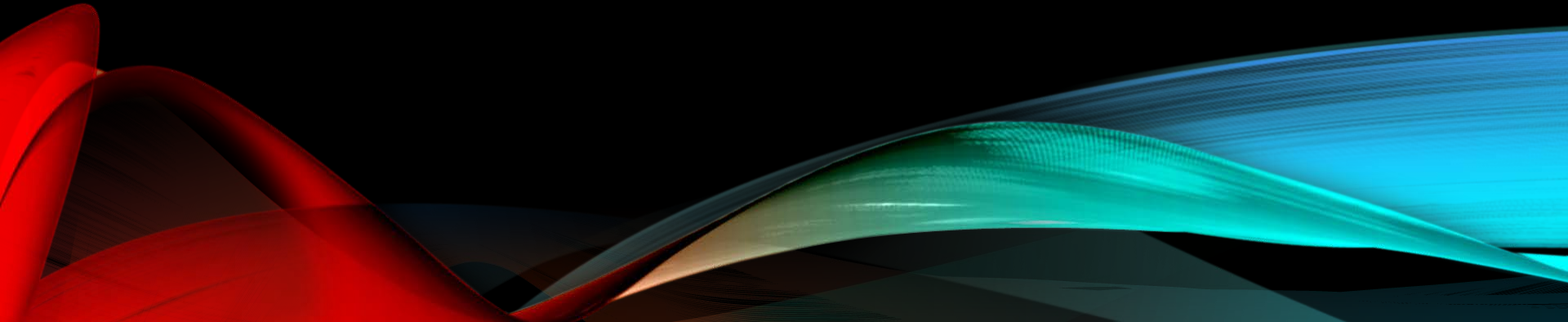
- Language preferences can of course be highly personal and in this conversation I will try to respect the different perspectives within our communities and the communities to which we will refer. Particularly with regard to terms such as NEURODIVERSITY, IDD, DISABILITY, CULTURE and TRAUMA I want to acknowledge that the collective understanding of these words is evolving currently and will have different meanings for different individuals inside and outside of their professional, conversational convenience.
- The very phrase “IDD” ??

TOPICS:

ADVOCACY

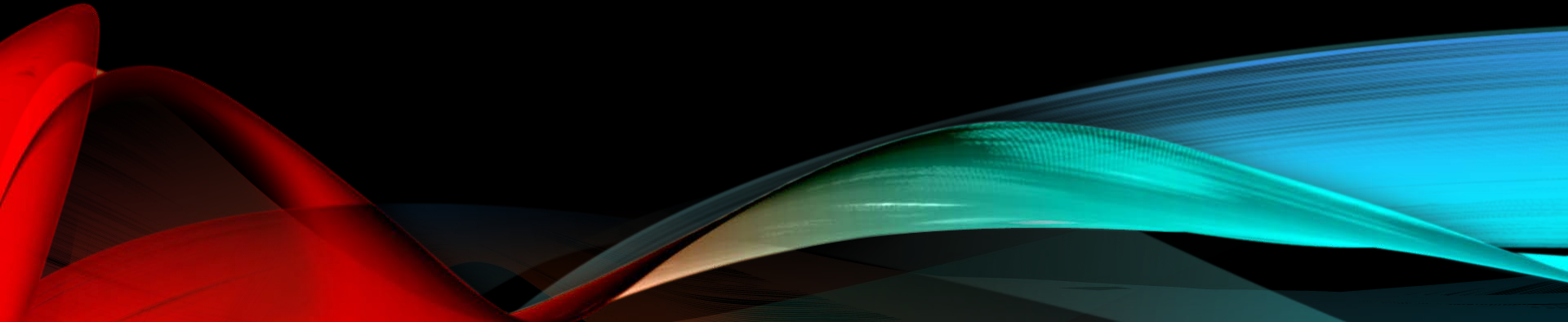
NEURODIVERSITY

SERVICE ENVIRONMENTS...BARRIERS



IF NOT NEW INFORMATION, CONVERSATION WORTH REPEATING

To improve understanding and communication,
we practice understanding and communication.



COMMUNITY SERVICES FOR PERSONS WITH IDD: ADVOCACY, NEURODIVERSITY AND SERVICE ENVIRONMENTS

The Arc of Somerset County

Mission Statement:

The Arc of Somerset County provides a lifetime of comprehensive services, advocacy and supports to individuals with intellectual and developmental disabilities and their families to promote growth, achievement and ongoing involvement in the community

- For many providers: Community setting, advocacy, fostering independence are vital service components and also present certain challenges...

ADVOCACY / SELF ADVOCACY

- As a provider supporting persons with and through all the intimate details of their lives, advocacy is an obligation – on a community scale, on an individual scale.
- Self-advocacy aside from an activity is a *movement*, a constant process by persons with IDD to represent themselves, to design services and to be a civic force as any group might aspire toward in its own interest.

From The New Jersey Self Advocacy Project:

The New Jersey Self-Advocacy Project (NJSAP) was established in 1983 to challenge individuals with intellectual and developmental disabilities to become involved in events, legislative policies, and issues that affect their lives or lives of others with disabilities.

We work together with these individuals to form The New Jersey Statewide Self-Advocacy Network (NJSSAN), which is used as means of supporting positive change on both a personal and social level...

[New Jersey Self-Advocacy Project \(arcnj.org\)](http://arcnj.org)

WHAT DOES THIS MEAN FOR COMMUNITY SERVICES OF ALL TYPES?

It means there is a group of citizens emerging into their independent conversation with our services...and more questions..

- To whom are we speaking? Our client/customer or their support provider?
- Who is providing our feedback?
- What community(ies) do we ask for participation and conversation in service design?
- Do we believe this community can inform us?
- Is our language presented to be widely understood?
- Does our conception of diversity include this group?
- ORGANIZED SELF ADVOCACY MEANS GOOD NEWS HERE.



NEURODIVERSITY* * * * * *

NEURODIVERSITY FROM:

[HTTPS://EXCEPTIONALINDIVIDUALS.COM/ABOUT-US/FREQUENTLY-ASKED-QUESTIONS-NEURODIVERSITY/](https://exceptionalindividuals.com/about-us/frequently-asked-questions-neurodiversity/)

What characterizes neurodivergent people?

- Struggling with reading and writing
- Clumsiness
- Finding it hard to cope with crowds, bright lights, loud, sudden noises, or social situations
- Difficulty with focusing or keeping still
- No smiling or social responsiveness.
- If you answered yes to any of the above, you could be neurodivergent.

FROM: [NEURODIVERSITY: WHAT IS IT?](#)
[\(WEBMD.COM\)](#)

- Judy Singer, a sociologist who has autism, started using the term "neurodiversity" in the late 1990s. It refers to the concept that certain developmental disorders are normal variations in the brain. And people who have these features also have certain strengths.

PLAINLY

- The term NEURODIVERGENT just like IDD, persons with Disabilities, etc. represents a WIDE SPECTRUM of people with vast differences in expressive and receptive communication in all forms and ease of adherence to typical or expected social agreements among other cognitive elements and patterns of behavior typically thought of as "skills".
- A diagnosis is not a personality.
- Our policies, our staff training our outward facing language, spaces and solicitation of stakeholder input can be better with regard to this multifaceted community. Ask an advocate, ask the person.

POSSIBLE USEFUL PARALLELS FOR THE FUTURE BEYOND SEMANTICS

- Cultural Competency / Neuro Competency
- Trauma Informed / Neuro Informed
- Barrier reduction for persons with....

EXAMPLES FOR US AS PROVIDERS: COMMUNICATING AND UNDERSTANDING ACROSS DIFFERENCES

- Our service language: Free samples at the doctor's office
- Our standards of participation in services at the library or rec program: Active / Passive *"My son is social"*
- Behavioral expectations at community college, public office: What is *"Against the rules"* Getting up, leaving, fidgeting; social safety vs. social success
- Who has authority at the point of service at the cancer treatment center: *"She does not know her date of birth; but she does know her address and if she is in pain..."*

SERVICE ENVIRONMENTS: A LONG EXAMPLE FROM HEALTHCARE

INDIVIDUALS WITH IDD:

- Tend to have poorer overall health and mental health status than their peers
- Clinical need, many have complex health profiles
- More chronic and more health conditions than non I/I/DD individuals
- Health conditions accumulation quicker than non I/I/DD individuals
- Lack of access to preventative health care
- Lack of support system and health management
- Limited transportation options leads to increased 911 calls
- State regulation compelling lay staff to contact 911 for certain or unknown situations

Continued...

- Basic and complex medical communication is often difficult
- Behavioral challenges may interfere with treatment
- Poor / inadequate information or history
- Follow up not coordinated or coordinated by non-medical staff
- 50% of all adults with Developmental Disabilities visit an Emergency Department in a 2 year period
- On average, those with I/DD visit the ED 3.0 times vs 1.7 time for those without I/DD
- On average, those with I/DD are 1.7 times more likely to be admitted than those without I/DD
- ED visits for those with I/DD can be anxiety producing and TRAUMATIC

CONTINUED...

- 25% of 18 to 24 year old Individuals with I/DD are taking 2 or more medications
- 50% of 35 year old Individuals with I/DD are taking 2 or more medications
- Poly-pharmacy is common among individuals with an I/DD.

CASE STUDY

- 27 y.o. male w severe autism spectrum disorder. Non-verbal.
- Recent behavior escalating to self-harm and harming caregivers after long stable period.
- ED referred to Psychiatry.
- Psychiatry referred to Medicine.
- Guess how long patient stayed in the ED?
- Guess what the final diagnosis was?

CASE STUDY

- Patient stayed 4 days in the ED and was prescribed a range of PRNs to “manage his behavior”
- Final Diagnosis → Dental Abscess
- Dental pain is a commonly missed diagnosis among individuals with I/DD and is a precipitant of behavior change

PATIENT AND FAMILY CONCERNS

- Lack of understanding of rights
 - Individuals with I/DD are presumed competent until proven otherwise by a court of law
- Unless someone has a legal guardian, they can consent to treatment
- Procedures cannot be forced onto an individual without consent from the individual or guardian
 - In the event of a conflict, a medical proxy can be consulted
 - Chemical and Physical restraint should only be used after alternative approaches have been tried

COMMON ED STAFF CONCERNS

- How can I engage with this person; we don't have that expertise
- We don't see a lot of individuals with I/DD, but when we do they are time consuming and difficult
- Sometimes the same person comes in 3 to 4 times in a row. Sometimes for seemingly minor concerns
- We are limited in the ED, we cannot fix a problem that has been brewing for years

ADAPTING YOUR APPROACH

- It is actually more effective to take your time with individuals with I/DD as you may reduce the rate of frequent returns- SEE tip sheet for communication
- Laying down the Law (Telling people what they can't/ shouldn't do) – will usually backfire and escalate the situation – talk about what they CAN do
- When discharging, make sure instructions are clear and/or there is someone to assist in follow up (this will reduce the need to return)
- Refer the individual to the Social Work or other departments to set up additional (long term) resources

REGULATORY CONSIDERATIONS

- Many individuals with I/I/DD live in group homes and apartments that are funded by Medicaid via the NJ Department of Human Services(DHS)
<https://www.state.nj.us/humanservices/>

Division of Developmental Disabilities (I/DDDD)

<https://www.state.nj.us/humanservices/I/DDd/home/index.html>

REGULATORY CONSIDERATIONS

- NJ DHS and NJ I/DDD regulate and license provider agencies that provide community living to those with I/DD and Mental Illness
- These regulations provide agencies/programs with standards that govern the care (Including health care) of those living in community residences
- Staff members in community residences are NOT health care professionals, but are provided training on best practices on supporting individuals with I/DD
- Many of the regulations that must be followed ; have provisions for a personal fine against the staff member – if not adhered to. Obligating staff to pursue treatment for items the general population would not.

DANIELLE'S LAW

In a life-threatening emergency,

**Don't Ask,
Just Call.**

Dial **9-1-1**

then **your
Supervisor**



New Jersey Department of Human Services

Prepared by DHS Office of Publications 10/2011

DANIELLE'S LAW

- This NJ law was enacted in to ensure staff members at facilities for individuals with I/DD call 911 when there is an life threatening emergency
- The essential message of the law is “when in doubt, call 911”
- The Law carries stiff personal fines for anyone violating the law
- The following 6 slides are excerpts from the Danielle's Law training that all facility staff members are required to take and pass

DANIELLE'S LAW

- Staff members who work in community residences for individuals with I/DD have an important role in caring for individuals with intellectual and developmental disabilities
- Recognizing medical issues and obtaining appropriate care is vital
- Emergency situations must be recognized and proper care must be obtained

Staff members actions can and do save a lives

DANIELLES LAW

- Life Threatening Emergencies are potentially fatal
- Not all medical situations are life threatening emergencies
- Staff members need to identify those situations that are life threatening emergencies vs those that are health threatening

DANIELLE'S LAW

- Examples of Health Threatening Conditions:
 - Sprained ankle
 - Bleeding controlled with pressure
 - Seizures typical to the person that last under 5 minutes
 - Minor burns/cuts
 - Flu symptoms
- If the health threatening condition worsens or becomes life threatening, call 9-1-1 immediately

DANIELLE'S LAW

- Examples of life threatening emergencies include, but are not limited to:
 - Unconsciousness
 - Persistent chest pain or discomfort
 - Not breathing or trouble breathing
 - Severe bleeding
 - Severe, persistent abdominal pain
 - Stroke symptoms
 - Post any choking event
 - Serious head injury
 - Shock
 - Some seizures

DANIELLE'S LAW

- Some questions to determine if 9-1-1 should be called:
 - ✓ Could this condition be potentially fatal?
 - ✓ Could the condition get worse and become life threatening if you drove the person to the hospital?
 - ✓ Could moving the person on your own cause further injury?
 - ✓ Does the person require the skills/equipment of emergency medical personnel?

DANIELLE'S LAW

- If you do not call 9-1-1 in a life threatening emergency, penalties may include:
 - Termination from employment
 - Fines up to \$25,000
 - Loss of license (For healthcare professionals)
 - WHEN IN DOUBT – CALL 9-1-1

DANIELLE'S LAW AND THE ED

- Many visits to the ED by those with I/DD are a result of a Danielle's Law – 911 call
- The 911 call is made by the staff member trying to ensure the best possible care for the individuals they support
- Staff members should accompany the individual to the ED to help facilitate communication and to provide additional health information about the person.

TIPS FOR EMERGENCY DEPARTMENT PROFESSIONALS

- Remember – All behavior is a form of Communication
- If possible , find out the preferred method of communication of the individual
- Address your communication to the individual first and then to the support person/family
- Ask about “baseline” traits – family , friends, interests, work, ambulation and recreation
- Ask the person to tell you or show you where the pain/ concern is

TIPS FOR EMERGENCY DEPARTMENT PROFESSIONALS

- Many individuals (especially those with autism) have sensory impairments – bright lights, noise, fabrics may cause distress – try to minimize when possible
- Tell the individual (and supporter) what you plan to do and get their consent, even for removing clothing or repositioning
- Avoid physically restraining an individual, as others may get injured; sometimes chemical restraint is safer

TIPS FOR EMERGENCY DEPARTMENT PROFESSIONALS

- Individual may experience post traumatic triggers in the hospital due to previous traumatic experiences, if an individual becomes aggressive, try to de-escalate with calm, specific communication.
- Do not try to “lay down the law” – it will only serve to re-escalate a situation
- Allow the person to advocate for themselves and give choices whenever possible (do you want the injection in your right arm or left arm?)
- Always provide feedback as you go along (“Thanks for letting me take your temperature”; “You’re doing a great job of sitting still while I take your pulse”)

IMPORTANCE OF KNOWING THE SERVICE ENVIRONMENT

If your service recipient is supported by "A system" it is likely that:

- Staff providing support are lay persons
- Only limited medical or other intervention may be legally possible
- Vague instruction or instruction sufficient for a family setting is not permissible
- While staff may be relied upon to transmit information; the default is to the person served

MUSTS / CAN'TS / MAYS

Medical/Behavioral

- MUST call 911 in certain prescribed instances regardless of
- Only specifically indicated items can be followed up upon
- As needed, twice per day, monitor behavior, contact provider as soon as possible, within 1 week, business hours, as directed, ASAP

Legal/Procedural

- Can not sign on behalf of
- Can not act as a guardian or POA might
- Can not exchange funds
- May have permission to exchange personal information
- May be relied upon to know personal history

3 BIG TAKEAWAYS

- Persons with IDD have and are organizing to represent themselves. As a group of stakeholders we hope to serve/expect to see in our spaces if we want to know something ASK AN ADVOCATE.
- Minimally for service providers NEURODIVERSITY means considering our work in view of another segment(s) of the population and striving to reduce barriers to service as we might in partnership with other groups.
- Service models for persons with IDD vary widely and may be governed by laws that change our service recommendations, language practices and typical procedures.

OTHER REFERENCES

- Approach to caring for developmentally disabled adults in the community; medical, ethical and legal considerations
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4301760/>
- Use of Emergency Departments among Working Age Adults with Disabilities: A Problem of Access and Service Needs
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3724353/>
- Working with Disabled People in the Emergency Department; Office of Developmental Primary Care; UCSF Department of Family and Community Medicine
- [Http://odpc.ucsf.edu](http://odpc.ucsf.edu)