



Challenges to Providing Services to People with Disabilities During the Pandemic

Pamela Stafford

September 17, 2020

Pstafford@ArcNM.org

Discussion Overview

- Framework for Discussion
- Medical Services
- Visitations
- Services Under the DD Waiver System

I/DD Susceptibility to COVID 19

- Conditions which cause Intellectual/ Developmental Disability do not put one at higher risk for COVID 19 and are not listed by the CDD as increasing vulnerability.
- A person could have autism or a cognitive disability and have no other underlying condition
- Persons with I/DD might have vulnerabilities (over 65, diabetes, cancer)
- Some conditions such as Down syndrome certainly have higher risk of other medical concerns including heart conditions
- Many persons with cognitive disability might have difficulty in understanding the need for a mask or social distancing.
- Congregate care settings do contribute to spread of COVID 19 with an increased risk the higher number of residents in settings

History of Isolation/Segregation for persons with I/DD

- History of Institutionalization
- Initially to protect persons with disabilities from the community
- Later to protect community from persons with disabilities
- The majority of states continue to have institutions although the populations are dropping
- Advocates have worked tirelessly for community services such as group homes and adult habilitation centers to not mirror institutional settings – not be mini institutions
- CMS final settings rules (now extended to March 17, 2023) mandates that those settings be more community focused and with an emphasis on individual rights
- Persons who live in Waiver operated group homes pay rent, room and board, have leases. Homes are not always owned by agency – sometimes owned by individuals. These are not licensed nursing homes. Supported living services are typically 3 or 4 persons in a home.

Health and Safety Balancing Act

- Everyone agrees that protecting individuals from COVID 19 is a priority
- Protection against COVID 19 has to be balanced with other harms that might occur due to isolation / lack of health care and therapy
- In an uncertain world agencies/ staff are operating the best they can but without always having clear information or guidelines There is often times confusion and misinterpretation of guidance.
- In some cases Interdisciplinary team members are pitted against each other – not because there are bad players- but have different perspectives.
- This is the most difficult time to be a service provider, a service recipient or an advocate

Medical Issues

- The Good News
- Visitation/ Supports in Hospitals

Medical Issues: The Good News

- We are all fortunate to be New Mexicans where quick actions prevented pandemic crisis numbers
- There is no doubt that the complete isolation of individuals with I/DD who live in group homes kept the numbers of confirmed cases and deaths within this population low.
- Priority allocation medical services and medical equipment in case of rationing in New Mexico does not include any language which devalues the life of individuals with developmental disabilities.
- The Public Health Order does require accommodations for individuals whose doctor has issued an order that they cannot or should not wear a mask.

Hospital Visitations/ Supports

- The ADA requires medical facilities to modify policies in order to assure access to medical care.
- During the initial lockdown period, restrictions were placed on visitations in hospitals
- While many hospitals allowed for some visitations for persons with I/DD, there are examples of persons not receiving appropriate bedside support to allow them full access.
- Since the restrictions lifted, some doctor offices have refused services to anyone living in a group home or nursing home, refused body scan to individual who would not wear a mask, and refused admittance of guardian to doctor appointments.
- Fortunately New Mexico never reached the crisis pandemic levels that other states such as New York reached, but that does not mean we are immune to future crisis

Examples

- Several situations of emergency room visits where the individual had guardians for medical decision making, but because the person was verbal, no staff or guardian was allowed to enter the hospital. The hospital staff wouldn't speak to the guardian over the phone (for confidentiality reasons) even when they had the guardian name listed on the paperwork. "Just call and talk to her. She seems to understand just fine."
- A parent who was allowed visit one hour a day, but not during hours of personal care (bathing). Patient who had never had anybody but family help with bathing was bruised. Parent wanted to help bath one time with the staff so the patient would get used to the support
- In New York, in midst of crisis rules were changed allowing individuals with I/DD to have bedside support. Quite frankly because not having bedside support was impacting other patients and health care providers
- Advocacy guidance created for parents and guardians by The Arc NM

Legislative Request

- A Bill to require Access to bedside support for persons with I/DD

During all health care crisis including pandemics Hospitals and medical offices must continue to make reasonable accommodations and modifications to policies to assure that persons with disabilities have equal benefit of medical services as other persons receiving those services. A family member or caregiver (patient care assistant, direct support professional, etc) should be allowed bedside access for all patients who normally require assistance with activities of daily living, communication support to understand healthcare information and follow healthcare instruction, and for behavioral support to mitigate behaviors that might challenge effective delivery. These supports are necessary accommodations to ensure equal access to healthcare, the safety of individuals with disabilities seeking hospital or clinic-based care and increased effectiveness and efficiency of health care staff.

Guardianship/ Family Issues

- Social Visitation Issues
- Restriction of personal liberties
- Monitoring Visits

Restrictions

- In early March during the initial lockdown, most advocates were supportive of the restrictions related to visits from family and guardian members
- In April/May some agencies began to make exceptions to allow individuals to go on family visits, DDS issued very clear guidelines that applied to **everyone receiving services** including those living in family homes and those receiving assisted living supports to maintain independence in their own single, community apartments

DDSD memo 21 issued 6/18/2020

- **DDSD Stay At Home Orders:** To be very clear, until further notice, all individuals receiving services administered through DDSD remain under the Stay At Home Order which includes not allowing visitation in or out of the home. Provider agencies should inform guardians and family members of this continued order. If the no visitation orders are not adhered to and a family member or guardian decide to pick up or remove an individual from services the individual will need to remain living with the family member or guardian until such time that the Stay At Home Orders are lifted. There are no exceptions to this rule as per the Department of Health Secretary. This directive regarding visitation supersedes all other previous visitation directives issued by DDSD.

Discrimination based on a single demographic

The Arc New Mexico took the position that to make blanket restrictions on **all persons receiving services** regardless of service category based on the single demographic of being intellectually / developmentally disabled was discrimination. No other higher risk category of individuals based on one demographic resulted in all persons of that demographic being restricted.

The virus has not created inequities in health care or personal civil liberties, but it has highlighted where inequities exist. The fact that it was so easy to restrict individual liberties based on a disability status should alarm all advocates who have strived for community inclusion and full civil liberties

Isolation

- Concerns from family members and guardians related to the fact of not being able to see individuals in group homes included
 - Increased in medication for anxiety
 - Severe weight loss
 - Severe weight gain
 - Bedsores
 - Bedbugs (identified in at least three agencies)
 - Medication error
 - Suicide attempts/mental health crisis
 - Many individuals feel/ feels that they are being punished.
 - Trauma retriggered

Changes August 1

- Beginning August 1, 2020 Provider Agency Nurses may resume face to face visits.
- Beginning August 1, 2020 Occupational Therapy, Physical Therapy, Speech Language Pathology, and Behavior Support Consultants may resume face to face therapy (clinical sessions) in the home.
- Beginning August 1, 2020 outdoor visitation may begin for Family Members and Guardians for individuals in Supported Living and Intensive Medical Living Services (please see the attached document for additional detail).
- Exception process for in home visitation implemented in September

Results of Visitation

- Within the first week-end, one set of parents discovered an arm injury that the staff had not noticed, another parent reporting her daughter eating and taking a shower for the first time in weeks.
- Challenges and struggles – not all guardians/ agencies have informed families that visitation was allowed, some agencies have restricted visitations to times when working parents cannot visits
- Some agency nurses do not want to go into homes, some therapists don't want to go into homes, some agencies don't want therapists to go into home.

Monitoring Visits

- Currently the visits outside and in home exceptions are for social visits only and do not allow monitoring visits into the home including to go into the bedroom or review some documents. It is possible we might be added to an exception process that has recently been approved.
- Med Errors – but guardians do not have access to look at MARs (Medication Assistance Records)
- Other reports- bugs, no food, one staff reporting that they heard another staff hitting a client, urination on the mattress without replacement – we cannot verify and cannot see.
- Agency supervisors, DHI, DDSD are not going into the homes- what can happen why we are “waiting”.

Services Under the DD Waiver

- Internet access
- Employment / Day Services
- Virtual services
- Direct Caregiver pay
- Congregate residential settings
- Opportunities

Internet Access as an Utility

- DDS expanded assistive technology fund
- The isolation and the monitoring issues were exasperated because internet access in the homes were not mandated until July 1, 2020.
- Even once mandated, confusion over whether or not services was mandated just for telehealth – some agencies saying no social visits, zoom visits, streaming. (there is an added cost to agencies)
- Sometime restrictions were based on keeping tablets etc locked up except when certain staff are available.
- Some staff do not have the knowledge base to help individuals access online
- Added burden residentially when with every other responsibility residential staff now has three people needing help on devices

Employment/ Day Service

- Some individuals were deemed essential and continue to work; some are waiting to to return work.
- DDS immediately suggested that stand alone day service and employment agencies staff be utilized in the home
- Many residential agencies did not allow this due to insurance or other reasons.
- Retainer payment initially authorized did not have clear guidelines
Now no longer available
- Agencies going out of business, staying in business but letting leases go, staying in business but laying off multiple staff

Virtual Services

- In a time when virtual work, school and leisure activities are normative, this has not been the case with individuals with I/DD
- Remote adult habilitation services can be billed effective September 1
- Cannot bill prep time and it does take time to “prep”
- Agencies are having to learn how to conduct classes with little assistance
- Cannot bill simultaneously with residential
- Little or no true community integrated activities –
- On the last point – now is a wonderful opportunity to enrich individual’s world with concerts, classes, workshops, virtual travel from around the world

Direct Care Staff Vacancy and Pay

- Low pay position with increased risk (staff working with COVID positive cases)
- More difficult to work with individuals who are isolated, scared, etc
- Difficult to get information on vacancy rate. Know some agencies have increased pay during COVID- others have not.
- Rate study completed in 2019 determined rates based on increase pay for direct support staff. Suggested amount \$15
- Allocation passed in 2020 included rate increased for agencies
- The pass through to direct support staff was not included.
- Now more than ever these essential workers deserve a higher rate of pay

Legislative Action Needed

- The rate increases are going into effect
- The money for these increases have remained intact.
- DDS has been advised they cannot require direct staff hourly wage increase without incurring third party employer liabilities
- Legislative action is needed to mandate a pass through of wages to support workers

Congregate Residential Settings

- Part of the final rule/ best practices of residential settings is that people can select their own roommates
- Across the country people without disabilities made COVID 19 living decisions such as moving home with their parents or health care professionals moving into their basements
- Part of the fear of visitations, etc into homes is the fear that, even if an individual has no underlying condition, they could bring the virus back to a roommate with underlying conditions
- Yet, there's been no widespread opportunity for individuals to discuss whether or not, given the current environment, who individuals are living with is appropriate or not. Some individuals might decide to restrict themselves more if they understand the danger connected to a roommate.

Opportunities to rethink services

- Adult Habilitation/ Employment services waiver changes already anticipating allowing individuals to stay home or have more flexible hours for service
- Closing of day sites allow agencies to think through more individualized services
- Online, recorded training for staff is seen by some to be a benefit
- Could virtual adult hab be provided with fee for class through existing waiver goods and services format
- Opportunity for virtual community integration where physical barriers might not be as challenging
- Opportunity to think through selection of roommates and who needs congregate settings.

A black chalkboard with the text "Any Questions?" written in white chalk. The text is written in a cursive, handwritten style. The word "Any" is on the top line, and "Questions" is on the bottom line. The chalkboard has some texture and light-colored smudges.

Any
Questions