



Prepared May 10, 2020

## Guidance Document

### **The need for known support (family, natural or professional) when individuals with I/DD are hospitalized during the COVID-19 emergency.**

The Arc New Mexico understands and endorses the need for social distancing measures during the COVID-19 emergency which includes limitation of visitors to hospitals when friends and loved ones are receiving essential care.

It is evident to The Arc New Mexico and those that support persons with I/DD that some individuals with I/DD, whether hospitalized for COVID-19 or other reasons, require support by others who know their support needs while in the hospital. If there is a legitimate need for support by a family member, natural support or a direct support professional, hospitals should recognize those needs and allow this support. Many times, to not allow that support jeopardizes not only the health of the individual, but sometimes other patients and hospital personnel as well.

The New Mexico Medical Advisory Team and New Mexico's Governor Office have indicated to The Arc NM that the Ethics Sub-Committee of the New Mexico Medical Advisory Team reviewed this issue and have encouraged medical providers to "work to assure that proper support is always available to hospitalized patients."

This document produced solely by The Arc New Mexico is to offer practical guidance and advocacy on this issue.

We encourage all individuals with intellectual/developmental disabilities, their family and support network, to plan for hospitalization before it is needed. In this document, we will outline:

- The difference between visitation and support
- What alternatives might be put into place that would not require a familiar face-to-face support
- Identifying and documenting the likely support needs of the individual
- Creating a document outlining support needs if supports are needed
- How to achieve individualized advocacy at the hospital to attain these accommodations

## Visitation vs. Support Needs

These are unusual times. Hospitals have restricted visitors of family members even in the most extreme circumstances. This is difficult for the patient and the loved one regardless of whether the patient is a person with a disability or not! Unfortunately, at this time the fact that the person has a disability does not require the hospital to allow visitors.

However, if a patient with a disability has support needs which are best provided by a familiar or known support person to minimize the risk of harm to either the patient, other patients or hospital personnel, then denying these supports may be a violation of an individual's civil rights.

In this situation and in these unprecedented times, it is important to clarify whether the request is of visitation vs. support needs.

## Consider Other Alternative Supports

Not every individual with I/DD will need specialized supports in a hospital stay. Some individuals might need some specialized support which the hospital itself could provide such as sign language interpretation or a sitter. If these supports are satisfactory, make sure information on behavioral support or supports at mealtime are provided. Training may also be provided via billing the Developmental Disabilities, Medically Fragile, or Mi Via Waivers if the individual is currently a recipient of these services (see Emergency Services Appendix K for clarification at:

<https://nmmedicaid.portal.conduent.com/static/PDFs/NM%20Combined%20Appendix%20K%2003-27-20.pdf>).

These are unusual times and the support network might be able to brainstorm support needs that, if the hospital agrees, would alleviate the need for familiar or known supports from outside of the hospital. These might include daily phone calls with the individual or virtual monitoring of the mealtime plan while the sitter supports the individual to eat. These requests may be documented in a letter to request accommodations for increased support needs.

## Identifying and Documenting Support Needs while hospitalized

Individuals and their support networks should discuss and plan for what support might be necessary when a person is in the hospital; these needs may be quite different from the medical needs that hospitals typically provide patients. We are listing some, but certainly not all support needs that individuals and their support networks should consider.

- Communication needs. Does the person require language specific supports, assistive technology, or that a communication plan be followed? How well does the person understand and follow directions? What about when an unfamiliar person is giving directions?
- Ability to understand and follow:

- Directions on how to summon assistance without getting out of bed
- Social distancing rules, including staying 6 feet from others and, e.g., not hugging people
- Not leaving one's room or wandering/going into other's rooms
- Wearing masks to protect others from infection
- Behavioral needs including anger outbursts, self -injurious behaviors, memory problems, disorientation, or risky behaviors such as pulling out tubes, not following personal hygiene protocols, or touching others inappropriately.
  - What are the "triggers" for these behaviors and what should others do to prevent or intervene when they happen?
  - Are these behaviors more likely to occur in an unfamiliar or hospital setting:
    - what assistance/ interventions help, and
    - how feasible is it that assistance can be provided by hospital personnel?
- Other specialized needs:
  - Are there mealtime plans to mitigate the risk of aspiration or assure hydration currently in place?
  - Does the individual have routines that should be approximated as much as possible in the hospital setting? If so, why?

### **Familiar Face-to-Face Support Needs Request**

If the individual and their support network determines that familiar or known support needs are the only realistic way to accommodate the individual's support needs, then the letter outlining the request for accommodation needs to clearly identify the details of that request. How will the support needs accommodation be fulfilled by family, natural or direct professional supports? Are the accommodations needed, during waking hours, or at certain points of the day? It is strongly recommended that supports be consistent. For instance, you might have two supports staff working 12 hour shifts each with one alternate staff to provide days off. Or you might have parents alternating days and a sibling staying at night. The fewer number of supports coming into the hospital will lessen the risk to the hospital personnel. Supports must be flexible to work with the hospital if they are restricting supports to leave the room very briefly for essential activities (bathroom breaks) or requiring screening when supports enter the hospital.

Additional documentation of the individual's concerns and needs in a letter to the hospital might include:

- Intensity and frequency of behavioral concerns,
- A clear indication of what might occur if the supports are not provided (this would be beneficial justifying the use of those supports)

- How the lack of supports might negatively impact positive medical outcomes for the patient and or/ other patients and hospital personnel (putting each at risk) may be very persuasive.
- If the document could be signed by medical professionals (primary care physician, mental health counselors or behavioral therapists or consultants for the individual that may certainly legitimize the request. If a person has a guardian, their guardian should always sign the letter.

### Individualized Advocacy

The Arc NM will continue system advocacy on these issues and all issues impacting individuals with I/DD during the current crisis. However, individual situations require individualized advocacy at the hospitals. While we can plan ahead to prepare for a crisis hospital visit, ultimately the advocacy will need to occur ***at the moment of crisis at the hospital itself. Direct support professionals, family living providers, residential service coordinators, family members, and guardians should have a protocol of who to contact and how to assure that advocacy is happening. This will, of course, be determined on an individual level.*** Remember to request a patient advocate if necessary or contact DDS Bureau of Behavioral Support Staff during regular business hours if the individual is currently receiving some form of DDW, SGF, Medically Fragile services, or is waiting for those services:

Metro (Bernalillo, Sandoval, Torrance, Valencia counties) [caroline.chavez@state.nm.us](mailto:caroline.chavez@state.nm.us)

Northeast (Colfax, Harding, Los Alamos, Mora, Rio Arriba, [sabrinaA.james@state.nm.us](mailto:sabrinaA.james@state.nm.us)

San Miguel, Santa Fe, Taos, Union counties)

Northwest (Cibola, McKinley, San Juan counties) [ryan.trujillo@state.nm.us](mailto:ryan.trujillo@state.nm.us)

Southeast (Chaves, Curry, De Baca, Eddy, Lea, Lincoln, [george.vigil1@state.nm.us](mailto:george.vigil1@state.nm.us)

Guadalupe, Roosevelt, Quay counties)

Southwest (Catron, Dona Ana, Grant, Hidalgo, Luna, Otero) [david.chavez3@state.nm.us](mailto:david.chavez3@state.nm.us)

### Resources:

[Coronavirus Health Hotline 1-855-600-3453](tel:1-855-600-3453)

[Coronavirus Information Hotline 1-833-551-0518](tel:1-833-551-0518)

[Crisis and Access Hotline 1-855-662-7474](tel:1-855-662-7474)

[The Arc New Mexico 505-883-4630](tel:505-883-4630)

[Disability Rights New Mexico 505-256-3100](tel:505-256-3100)