

September 30, 2020

Anne Marie Costello, Acting Director of Center for Medicaid and CHIP Services (CMCS)
Michelle Schreiber, Deputy Director for Quality and Value, CMS Center for Clinical Standards and Quality (CCSQ)
Melissa Harris, Acting Director, CMS, Disabled and Elderly Health Programs Group (DEHPG)
Evan Shulman, Director, Division of Nursing Homes, CCSQ
Joann Fitzell, CCSQ
Don Howard, CCSQ
Lillian Williams, CCSQ

Sent via email

Re: CMS September 17, 2020 “Nursing Home Visitation – COVID-19” Guidance

Dear Ms. Costello, Ms. Schreiber, Ms. Harris, Mr. Shulman, Ms. Fitzell, Mr. Howard, and Ms. Williams:

Thank you again for meeting with us on August 14, 2020, to discuss visitation policies in congregate settings. At that meeting, we discussed the need for CMS to issue additional guidance describing the circumstances where congregate facilities – including nursing homes, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), psychiatric facilities, assisted living facilities and group homes – must make reasonable modifications to their visitation policies to allow residents to access in-person supports/visitors consistent with federal disability laws and policies. We also discussed the importance of providing additional guidance and best practices to congregate settings about strategies for safely increasing visitation opportunities for all types of visitors.

We would like to thank you for the “Nursing Home Visitation – COVID-19” guidance issued by the Center for Clinical Standards and Quality (CCSQ) on September 17, 2020. We believe it is a helpful initial step in addressing the serious concerns facing nursing home residents. Specifically, we appreciate that the guidance:

- Makes clear that facilities must comply with federal disability right laws, including the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, when in-person supports are necessary to ensure equal access to care (including by ensuring effective communication)
- Recognizes that Protection and Advocacy (P&A) programs have a legal right to immediate and unrestricted access to residents
- Clarifies the range of circumstances that constitute “compassionate care visits” that should be allowed even when regular in-person visitation may be limited and that those types of visits may involve, consistent with safety protocols, personal contact
- Prohibits restrictions to in-person visitation without a reasonable clinical or safety cause and requires nursing homes to allow visitation consistent with the guidance

We were dismayed, however, that this guidance applies only to nursing homes, despite residents of other congregate facilities – including institutional settings like ICF-IIDs and psychiatric hospitals and HCBS-funded congregate settings like assisted living and group homes – facing the exact same issues. It is particularly confounding given that CMS has previously issued guidance about visitation in these other settings.¹ Moreover, the disability community has repeatedly raised concerns with CMS, ACL and OCR about HHS issuing guidance about residents of nursing homes while failing to address people with disabilities in other similarly situated congregate settings.² This includes issuing regulations that mandate reporting and notifying residents of COVID-19 infections and deaths only for nursing homes, creating a safety commission focused on COVID-19 only in nursing homes, and issuing regulations mandating testing only of nursing home staff and residents. **We implore CMS to immediately issue additional guidance covering visitors to other institutional and congregate settings. The rights and well-being of residents should not depend on whether they happen to be living in a nursing home or other Medicaid-funded congregate setting.**

While the guidance is an important step forward for nursing home residents, there are several important issues that remain unclear or unaddressed in the current version that we encourage you to clarify in future guidance. These include:

- **Community providers assisting with transition:** As we discussed at our meeting, we are hearing from people across the country whose transitions from nursing homes or other institutions to the community have been stalled due to facilities applying no-visitor policies to prevent entry of community providers working with those residents. The new guidance states that outside health care workers and other service providers “must be permitted to come into the facility as long as they are not subject to a work exclusion due to an exposure to COVID-19 or show signs or symptoms of COVID-19 after being screened.” There is no mention, however, about this applying to providers assisting with transition, and community providers are not included in the list of examples of health care workers and service providers for whom entry is mandated. Given that the transition of people with disabilities and older adults implicates their civil rights under the Americans with Disabilities Act and Supreme Court’s *Olmstead* decision, we think it is crucial that this guidance be clear that providers assisting with transition must be permitted in-person visits.³
- **Types of legally mandated visitors:** It is critical that residents’ outside supporters/visitors be able to understand from this guidance when they have a right to

¹ See attachment with relevant language from CMS and CDC guidance that we provided to you prior to our meeting.

² See, e.g., April 21, 2020 Letter regarding CMS Nursing Home Transparency Initiative (available at <http://www.c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-institutional-and-congregate-care-and-COVID19-final.pdf>); May 5, 2020 Letter regarding CMS Nursing Home initiatives (available at <http://www.c-c-d.org/fichiers/LTSS-Co-Chair-Letter-re-COVID19-and-CMS-nursing-home-safety-initiative-5-5.20-to-CMS.pdf>); and July 7, 2020 Letter regarding CMS Interim Final Rule on nursing home reporting requirements (available at <http://www.c-c-d.org/fichiers/Nursing-Home-Reg-Comments-final-7-7-20.pdf>).

³ We appreciate CMS’s recent announcement about additional funding available to states’ Money Follows the Person programs (available at <https://www.cms.gov/newsroom/press-releases/cms-announces-new-federal-funding-33-states-support-transitioning-individuals-nursing-homes>). Clear guidance about in-person visits by providers working on transitions is crucial to the success of states’ MFP programs.

visit.⁴ Without clarity, individual facilities will continue denying residents critically important access to support persons and visitors when they are entitled to access by law or guidance. We request that CMS clearly state that facilities must permit visitors and support persons for the following purposes, even if the facility is otherwise limiting in-person visitation, unless the support person/visitor has COVID-19 symptoms or refuses to comply with the facility's infection control practices: (1) compassionate care visits; (2) visits by P&As and ombudsmen; (3) in-person supports necessary for equal access to care and effective communication under disability rights laws; and (4) outside healthcare and service providers, including providers assisting with transition.

- **Implementation and enforcement:** A number of states have guidelines in place that are more restrictive than this guidance and have indicated they will not implement the CMS guidance. How will CMS ensure that states and facilities align their policies with this new guidance? We appreciate that this guidance states that failure to adhere to it may subject a facility to citation and enforcement action (p. 5, 6). But the guidance does not provide information about how and to whom to report non-compliance. It also does not direct state survey agencies to investigate alleged non-compliance in a timely manner. These issues must be addressed in order to ensure that residents' rights are protected in accordance with this policy.
- **Ombudsmen and P&As:** We are pleased that the guidance recognizes the important roles that both P&As and ombudsmen play in protecting the rights of people in nursing homes and that they have a legal right to access. Yet the guidance says that Ombudsmen's in-person access "may be limited due to infection control concerns...." We believe that Ombudsmen, like P&As, should be permitted access at all times. In addition, future guidance should clarify that P&As have access not only for investigations of abuse and neglect but also for monitoring activities and to all people with disabilities⁵ and the locations where they receive services and treatment.
- **Circumstances and safety protocol when direct physical or proximal contact may be necessary:** There are some circumstances where physical or proximal contact between a support person/visitor or outside service provider and a resident may be necessary. This may include when a resident needs support to communicate using tactile sign language or augmentative and alternative communication, when a support person/visitor assists with feeding or other self-care needs, or when a resident is being transitioned out of a facility. We request that CMS clarify the circumstances and safety protocols when physical or proximal contact is necessary. We believe that these limited situations can be handled safely by subjecting support persons/visitors to similar protocols that are in place for facility staff, such as COVID-19 screening and facility-provided PPE.

⁴ The guidance refers to a number of kinds of visitors, including "essential visitors" (p. 4), compassionate care visitors (p. 4), disability-related support persons (p. 6), and other visitors, and states that facilities should use a "person-centered approach" when applying this guidance (p. 4).

⁵ The guidance document refers to P&A access authority under the DD Act and PAIMI program. P&As also have access under the P&A for Individual Rights (PAIR) program, which covers individuals with disabilities other than developmental, intellectual or psychiatric disabilities.

- **Virtual visitation:** We appreciate that the document recognizes the importance of social visitation. It states that in-person visitation must be facilitated consistent with this guidance and that failure to facilitate in-person visitation without a clinical or safety reason would be subject to citation and enforcement action. Yet the document does not clearly state that alternative methods of visitation must be facilitated when in-person visitation is not possible. We ask that CMS clarify this point.

Thank you again for issuing the “Nursing Homes Visitation – COVID-19” guidance. It will make a positive difference in the lives of nursing home residents and their families. We look forward to working with you to ensure this guidance is expanded to other institutional and congregate settings and clarifies remaining issues. We would welcome the opportunity to have a discussion with you about this and further guidance on visitation. You can contact Alison Barkoff (abarkoff@cpr-us.org or 202-854-1270) for any questions or follow up.

Sincerely,

Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Center for Public Representation
CommunicationFIRST
Justice in Aging
National Consumer Voice for Quality Long-Term Care
National Disability Rights Network
The Arc of the United States

Cc: Roger Severino, Director, Office of Civil Rights (OCR)
Robinsue Frohboese, Principal Deputy Director, OCR
Lance Robertson, Administration, Administration for Community Living (ACL)
Vicki Gottlich, Director, ACL Center for Policy and Administration

Attachment: Summary of CMS and CDC visitation guidance documents