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Cover Page Footnote

The research findings discussed in this manuscript have previously been presented at conferences for the following organizations: American Association on Intellectual and Developmental Disabilities (poster); Council on Social Work Education (poster); Gerontological Society of America (oral); International Association for the Scientific Study of Intellectual and Developmental Disabilities (poster); and University of Wisconsin-Madison Institute on Aging (poster). This study was not supported by any external fundings. The authors have no known conflict of interest. The authors wish to express their gratitude to the various state officials and developmental disability planning council members who assisted in identifying and confirming the documents analyzed for the purposes of this study.

Advance Care Planning Within Individualized Care Plans: A Component of Emergency Preparedness

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Abstract

Federally legislated Medicaid requirements for recipients with intellectual and/or developmental disabilities (IDD) to have a person-centered plan (PCP) do not specifically state that advanced care plans (ACP) be a component of the plan. However, coronavirus disease 2019 (COVID-19) has provided a salient reminder of the importance of incorporating ACP within the PCP for people who have IDD. As demonstrated by situations arising from COVID-19, emergencies and crises can dramatically alter access to care for people with IDD. This paper synthesizes results from an environmental scan related to ACP for adults with IDD. Findings suggest that the use of ACP, particularly when such planning processes result in the delineation of roles and documentation of preferences, can be helpful in mitigating the impact of these crisis situations on the person with IDD and their caregivers.

Plain Language Summary

People with a disability who receive services from the government for their disability have to have a written plan about their life. Plans for the future do not need to be part of this written plan. However, with the COVID-19 pandemic, we see more emergencies that cause big changes to the lives of people with disabilities. During big events like this, it can be helpful to have plans for the future written down. In this paper, we look at what is known about planning for the future for adults with disabilities. We make suggestions to improve these plans so people with disabilities and their caregivers feel more prepared during a crisis.

Keywords: Advance care planning, intellectual & developmental disabilities, person-centered plans, caregiving, end-of-life, decision-making, emergency planning

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Health policy, planning, and practice often fail to meet the needs of people with intellectual and/or developmental disabilities (IDD), especially in response to unforeseeable emergencies (Nygren & Lulinski, 2020). An example of this is the coronavirus disease 2019 (COVID-19) pandemic (Avalere Health, 2020; Courtenay & Perera, 2020; Hughes & Anderson, 2020; Willner et al., 2020). Throughout the COVID-19 pandemic, public policy has often failed to adequately support people with IDD and their caregivers (Center for Public Representation, 2021). The ongoing pandemic has revealed the necessity of emergency planning and also the longstanding absence of it in the lives of people with IDD (Miceli, 2020).

More specifically, COVID-19 has provided a salient illustration of the need to integrate advance-care planning within the mandated person-centered planning process for those receiving Medicaid home- and community-based services (HCBS). Implementation science demonstrates that capacity building using evidence-based frameworks in health care and public health settings are requisite to influence policy and achieve funding to enable effective evidence-based service provision (Metz et al., 2015; National Institutes of Health, 2019; Pollastri et al., 2020). Identification and articulation of the measures and practices necessary to guide an emergency response in the service of people who have IDD on an ongoing basis is needed in order to ensure policy and funding, which enable effective responding to these emergencies. This is particularly so in the face of population-level emergencies, whereby there are competing demands for public resources to respond to the emergency.

In this brief, we contend that advance care plans (ACPs) are integral to the maintenance of care and services during unanticipated crises, and, as such, warrant inclusion in requisite person-centered plans (PCPs), which may also be known as life-care plans (LCP). For brevity, they will be referred to as PCPs throughout this paper. Drawing upon a human rights perspective, we offer recommendations for policy and practice that harness lessons learned from the COVID-19 pandemic to ensure that the person-centered planning process attends to emergency preparedness, including advance-care planning for people with IDD and their caregivers. We argue that doing so prior to emergency situations increases the likelihood of maintaining principles of independence, participation, care, self-fulfillment, and dignity when such circumstances do arise.

Advance-Care Planning for People with IDD

Advance-care planning is defined as the development of a care plan in preparation for when one's diminished capacity prevents decision-making for oneself (Perkins & van Heuman, 2018). Considerations reflected in an ACP may include: (a) wishes for one's future, (b) residential decisions, (c) financial considerations, (d) occupational and recreational preferences, (e) supportive measures to facilitate daily living and life-course transitions, and (f) maintaining a social support network (Arc Center for Future Planning, 2016). ACP tends to result in a better-informed care during crises—especially when it is completed as a collaborative process, informed by key stakeholders, and reflective of the values and priorities of the person for whom it is being completed (Arnold et al., 2012; Bigby et al., 2015; Heller & Caldwell, 2006; Heller & Kramer, 2009).

ACP is distinct from the more generic ACP process that people who have IDD complete with their care team in that the focus on the LCP tends to be on arrangements within the context of day-to-day living. Conversely, ACP specifically accounts for decision-making in unforeseeable crises and emergencies. Unlike LCP, the focus of ACP often includes consideration for palliative care, funeral and burial, as well as transition of care following incapacitation of caregivers.

Where PCPs aim to facilitate autonomy and life satisfaction experienced by the person with IDD, completion of the ACP process tends to result in better-informed care during both individual and population-level emergencies and crises. This is especially so when it is completed as a collaborative process, informed by key stakeholders, and reflective of the values and priorities of the person for whom it is being completed (Arnold et al., 2012; Bigby et al., 2015; Heller & Caldwell, 2006; Heller & Kramer, 2009). Resource allocation to the ACP process is crucial to effective implementation of services in emergencies and crises.

Yet, few Americans have completed ACPs, with Yadav et al. (2017) estimating that only about one-third of Americans have these plans in place. Healthcare providers, who are arguably well-positioned to initiate conversations regarding ACPs, reported avoidance of this process because of the discomfort and difficulties these emotionally laden conversation can evoke (McEnhill, 2008). For people without disabilities, Voss (2017, 2019) indicated a trend toward increased use of advance directives, particularly among people with IDD with serious illnesses. However, many people within the disability community remain reluctant to participate in the ACP process because of concerns of misuse of the plan to rationalize withholding of care (Center for Public Representation, 2021; Johnson, 2010). The COVID-19 pandemic appears to have exacerbated these fears.

Family Caregivers and Future Planning

Less than a one-half of maternal caregivers between the ages of 58 and 87 years of age reported completing ACPs for their children with IDD (Freedman et al., 1997). Parents of adult children with IDD cite a lack of options available, indecision, and frustration navigating obstacles as reasons for delaying or forgoing the ACP process (Taggart et al., 2012). Among the most significant of barriers was parents' deep-seated fear of a future when they could no longer provide care for their children (Haley & Perkins, 2004; Marsack-Topolewski & Graves, 2020). However, an ACP educational program was found to alleviate parents' planning challenges. A study of this intervention found that the prospect of planning became less intimidating when caregivers had access to opportunities to become familiar with ACPs (Heller & Caldwell, 2006).

Informal caregivers (i.e., unpaid and/or family caregivers) can abruptly become disabled or unable to provide care, requiring coordination of care for themselves as well as their loved one with IDD (Kuper et al., 2020). In situations that require informed consent from the caregiver, sudden changes in the caregivers' capacity can affect decision-making and care arrangements for the individual with IDD (Alexander et al., 2020). A pre-existing ACP delineating transfer of decision-making and emergency care can help to alleviate burden during times of emergencies. Providing care and meeting the needs of people with IDD throughout the COVID-19 pandemic

provides a salient example of an unanticipated circumstance that could require provision of alternative care arrangements on short notice.

Learning from the COVID-19 Pandemic

Because of the unexpected impact of COVID-19, families and people with IDD have encountered significant challenges (Hughes & Anderson, 2020). While some of these disruptions have been mitigated by technology, the ongoing pandemic has resulted in statewide closures of needed resources, services, and supports (Avalere Health, 2020; Hughes & Anderson, 2020; Rose et al., 2020). A nationwide survey, administered to 1,600 community service providers for people with IDD, found that as a result of COVID-19:

- 68% of service providers were forced to close,
- 52% of remaining services had to increase spending for staff overtime, and
- 57% of providers struggled to adequately staff services, such that they were sometimes unable to offer them (Avalere Health, 2020).

In response to the COVID-19 pandemic, medications had to be modified in some cases to address hyperarousal and anxiety resulting from extreme, ongoing, and uncontrollable changes (Hughes & Anderson, 2020).

Global circumstances arising from the early months of the COVID-19 pandemic illustrate how a novel virus with no cure or treatment can impact the delivery of care. Emergencies require caregivers to respond and adapt to new realities (e.g., lockdowns and physical distancing measures, interruptions to supply chains, caregiver attrition). These realities influence and limit when, how, where, and what care can be delivered. Regardless of availability of formal caregiver support, family caregivers were often expected to navigate challenging circumstances while balancing other life responsibilities (Grier et al., 2020). While COVID-19 yielded many unexpected challenges, caregivers who had engaged in ACP may have been able to minimize disruptions in care.

Emergency Preparedness: A Human Rights Perspective

Members of the United Nations (UN) have responded to the recommendations of international institutions, such as the World Health Organization (WHO) and the International Association for the Scientific Study of Intellectual Disabilities (IASSID), to prioritize policy development, capacity building, and research to support adults who have IDD as they age (Evenhuis et. al., 2000; Hogg et. al., 2000; Thorpe et al., 2000). The guiding principles informing these initiatives are similar to those adopted by the UN General Assembly in the *United Nations Principles for Older Persons* (resolution 46/91), as well as those identified in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2012). These include: (a) independence, (b) participation, (c) care, (d) self-fulfillment, and (e) dignity. Unfortunately, the abstract nature of these characteristics makes them challenging to quantify and generalize

across populations. These challenges have been exacerbated by the pandemic, which has made it not only difficult to measure adoption of these principles but also posed unrelenting challenges to enacting policies that uphold them.

Service closures and physical distancing requirements resulted in innumerable people who have IDD losing access to essential services; thereby, increasing the burden on many families to provide care (Avalere Health, 2020; Rose et al., 2020). However, little regard is devoted to the condition of the individual or the family's ability to meet those needs. The extant research on ACP with people who have IDD has focused on planning in the absence of a global pandemic. Emergent knowledge suggests that PCPs were often insufficient in articulating ACPs during this particular emergency situation (Miceli, 2020). When systems fail to adequately prepare for or have difficulty enacting policies in the wake of foreseeable unforeseen events, the climate exists where it can become increasingly difficult to uphold the guiding principles of independence, participation, care, self-fulfillment, and dignity.

Discussion

Given the inevitability of emergencies, people with IDD will need to maintain access to care and support throughout unexpected situations. Planning is needed to manage potential changes that affect people with IDD, family caregivers, and service providers. COVID-19 has provided a particularly salient illustration of an emergency situation that could have benefited from the intentional and widespread integration of ACP within the PCP process. Given the increased likelihood of people with disabilities, including those with IDD, to be infected and/or die from the virus, a pressing need exists to maintain continuity of care in such emergency situations (Pineda & Coburn, 2020). An ACP can help mitigate these challenges, along with others related to care and service access.

Medicaid now requires that each individual receiving services through the HCBS waiver have a PCP (U.S. Department of Health and Human Services [USDHHS], 2015). This rule change provides a prime opportunity for considering ACP. As the PCP process must be completed at regular intervals, the ACP can be updated to reflect changing caregiver arrangements and planning for emergencies. This process can also build familiarity and comfort with planning across the lifespan. Incorporating ACP into the PCP as a standard practice can serve to alleviate distress on the part of the person with IDD, family caregivers, and health care providers when crises arise.

The UNCRPD offers guiding principles that can inform the enactment of policies and practices for the integration of ACP in the PCP process. Yet, the focus of UNCRPD is on the home and family, particularly the rights of people who have IDD and caregivers to children with IDD. There is no provision made for family caregivers of adults who have disabilities. Lifelong disabilities, however, do not end upon entry to adulthood. Frequently, access to supports familiar to the person with a disability and their family are offered to children through the school. With the transition to adulthood and exit from the school system, these supports cease to be available. As such, alternative supports and plans need to be put in place.

In a community-based care setting, which seems to be the service model of choice among UN member nations, failure to account for adults who have disabilities and those who assist or care for them may hamper their ability to benefit from the principles articulated in the UNCRPD. The absence of such considerations can create perilous scenarios for both the caregivers and person with IDD in emergency situations. When these scenarios are not accounted for in health policy, mechanisms to adapt to such circumstances are limited.

Family caregivers have experienced these challenging circumstances throughout the COVID-19 pandemic, such that many have reported defeat, anxiety, and depression (Willner et al., 2020). Some family members, particularly in the case of older adults with IDD, have found themselves incapacitated and requiring emergency care services for themselves as well as people with IDD (Rose et al., 2020). Family caregivers have had to become nimble when identifying and accessing alternative support services during the pandemic. Where barriers to care arise, it is the role of the relevant professionals to assist the parent or family member to identify what options exist to meet the needs of their loved ones. Emergency planning can be incorporated within the person-centered planning process. The knowledge that this has been accounted for and is likely to reflect the individual's values and needs, can serve to alleviate parental fear for the future—a previously identified barrier to engaging in the planning process.

Building ACP into the PCP process provides an opportunity for the person with IDD to develop familiarity with transitions and changes to routine that can arise from emergencies and crises. A documented plan for navigating emergency situations, specifying who will be responsible for fulfilling various roles and needs, can ensure more accountability in and effective delivery of care and support in spite of foreseeable unforeseen circumstances. Accounting for dietary preferences and restrictions, behavior management protocols, and individual values/priorities can ease disrupted circumstances. Accounting for finer details, such as end-of-life planning, can also ensure that one's values and priorities can/will be upheld. This has become particularly important during the COVID-19 pandemic when caregivers and surrogates were often prevented from being present with the person with IDD through the changed circumstances.

Service providers can help their clients plan for emergencies by engaging people who have IDD and their families in the ACP process. The PCP process, a required element for those receiving Medicaid-funded services, is an ideal setting for discussing and documenting ACPs. Doing so may help to ensure that individuals with IDD, as well as their family and members of their care team, understand what to expect and know how to minimize disruptions as crises emerge.

Recommendations for Practice

1. Systematically desensitize the anxiety associated with ACP by incorporating it within the regularly scheduled person-centered planning process, allowing people with IDD and their families regular exposure to practical and supported discussions about relevant arrangements when no emergency or crisis is imminent.

2. Embed and regularly update stress mitigation strategies within the PCP documents, accounting for foreseeable unforeseen circumstances, such as emergencies and crises, which may necessitate temporary or permanent alternations to care arrangements.
3. Ensure that a mechanism for keeping current features within the PCP documents, such that it will serve to maintain a semblance of stability across alternate care arrangements (e.g., dietary preferences and restrictions, favored pastimes, fears, preferred clothing, and/or comfort items, etc.).
4. Formalize and implement plans to rehearse emergency responses (e.g., alternate care accommodations, communication of the need for alternate care, etc.) regularly so that alternate care circumstances are not foreign to the care recipient at the time of crisis response.
5. Include alternate care providers in the rehearsal process, thereby achieving role clarity, identify possible challenges, and resolving any issues that may arise prior to the eventuality of an emergency or crisis situation.

Conclusion

In general, people are hesitant to engage in the ACP process. This is particularly so among people who have IDD and their loved ones. However, having an ACP is especially important among this population, as it can facilitate safe and effective responding to emergency situations. The current COVID-19 situation, worldwide, has provided a salient example of how people with IDD have been impacted by unforeseen loss of access to services and sudden changes to their care and living arrangements. The effect has been, in many situations, circumstances that compromise one's ability to live in ways consistent with principles of human rights for both those who have disabilities, including IDD, and people who are aging (i.e., people with IDD and/or their family members). Developing an ACP, within the context of a PCP, a plan that is legislated for updating at regular intervals, can facilitate a clear approach to support and care consistent with one's values when emergencies arise.

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