1-1-2024

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Recommended Citation

Andrea Barton-Hulsey, Miriam C. Boesch, Yoosun Chung, Tina Caswell, Amy Miller Sonntag, and Wendy Quach. "Emergency and disaster preparedness for individuals who use augmentative and alternative communication: A pilot study on supported planning using a toolkit" *American Journal of Speech-Language Pathology* (2024): 16-32. https://doi.org/10.1044/2023_AJSLP-23-00086

ASHA American Speech-Language-Hearing Association

AJSLP

Clinical Focus

Emergency and Disaster Preparedness for Individuals Who Use Augmentative and Alternative Communication: A Pilot Study on Supported Planning Using a Toolkit

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ARTICLE INFO

Article History:
Received March 8, 2023
Revision received June 12, 2023
Accepted August 30, 2023

Editor-in-Chief: Erinn H. Finke
Editor: Billy T. Ogletree

https://doi.org/10.1044/2023_AJSLP-23-00086

ABSTRACT

Purpose: When emergencies or disasters arise, individuals who use augmentative and alternative communication (AAC) are particularly vulnerable. It is critical that individuals who use AAC are supported to make decisions that impact their own lives and are able to communicate during such a crisis. Preparedness efforts that include a plan around communication needs and supports are necessary for ensuring that individuals who use AAC are able to understand options that ensure personal safety and express their needs during a time of crisis.
Method: Qualitative methods were used to identify and describe the experiences of two young adults who use AAC and their caregivers when engaging in person-centered planning intervention sessions to complete the activities of the United States Society for Augmentative and Alternative Communication (USSAAC) emergency/disaster preparedness toolkit. Pre-intervention interviews and subjective, objective, assessment, and plan (SOAP) notes taken after each intervention session were done to describe their preparedness and experiences completing the toolkit. Themes were identified to describe participant experiences and change in their perceived preparedness.
Results: Five themes and 18 subthemes emerged from the pre-intervention interviews and the SOAP notes across 14 intervention sessions that captured each participant and their caregiver's awareness of needs, barriers in emergency situations, challenges in completing the toolkit, and actions during person-centered planning with the toolkit (e.g., personalizing communication boards, making a go bag, and scheduling visits with local emergency agencies).
Conclusions: This study highlights the need for preparedness activities that are person-centered and account for the communication support needs of individuals who use AAC if faced with an emergency/disaster. Outcomes suggest that these methods were feasible and supported positive change in perceived preparedness in the young adults who used AAC and their caregivers.
Supplemental Material: https://doi.org/10.23641/asha.24415567

Rescue and relief efforts following natural or human-imposed emergencies and disasters give rise to numerous situations in which communication is vital for positive outcomes. Emergency/disaster preparedness provisions are a critical investment and shared public health responsibility between local community and government

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Disclosure: *All authors are members of the USSAAC Disaster Relief Committee. However, the content is strictly the authors' own views.*

systems and the individuals who live within those regions (Kruger et al., 2018).

Individuals who use augmentative and alternative communication (AAC) are particularly vulnerable during times when emergencies/disasters arise. AAC is a type of assistive technology (AT) for individuals who have no or limited speech. Examples of AAC include picture cards, communication boards, and communication applications on tablets/desktops/laptops. The generation of words and messages using AAC often takes longer than speech to communicate. However, rapid communication is required to take actions that ensure personal safety. Preparedness efforts that include a focused plan around communication strategies and supports are necessary for ensuring individuals who use AAC are able to express their needs during a time of crisis (Blackstone & Kailes, 2015).

When faced with an emergency or disaster, displaced individuals may encounter a variety of workers that include first responders, nurses and doctors, volunteers in first aid posts, counselors, and caregivers in distress centers and housing shelters. Specific AAC strategies and information for workers about these individualized needs can support individuals whose communication has been affected by the emergency or disaster (Blackstone & Kailes, 2015).

Although international and national organizations have plans that address preparedness, rescue, and relief efforts, issues of communication are rarely considered. This study will describe the emergency/disaster preparedness of two young adults who use AAC and their caregivers and describe the outcomes of engaging in person-centered planning sessions using an emergency/disaster preparedness toolkit for each family.

Emergency/Disaster Preparedness Provisions for Individuals With Disabilities

Through the Americans with Disabilities Act (Americans With Disabilities, 1990), federal guidelines require the integration of the needs of people with disabilities in emergency/disaster preparedness plans. The U.S. Department of Health and Human Services (HHS) is responsible for providing guidance that is uniquely focused on individuals with disabilities. The HHS office on disability, the Federal Emergency Management Agency (FEMA), and the Public Health Emergency Preparedness (PHEP) program work together to provide resources and guidance that can be utilized by states and local government authorities (Kruger et al., 2018). It is then the responsibility of states and local communities to implement these preparedness efforts and identify specific needs of individuals within their communities. Various state, national, and international organizations have developed preparedness plans (e.g., Red Cross, European Civil Protection and Humanitarian Aid Operations, and Public Safety Canada); however, limited information addresses communication supports for people with disabilities.

In order for individuals with disabilities to adequately access resources of need during the time of an emergency or disaster, they must be able to engage with those resources using largely language-based activities. A function-based approach to preparedness is described by Kailes and Lollar (2021) as including five areas of need for individuals with disabilities: (a) communication, (b) maintaining health, (c) independence, (d) support, safety and self-determination, and (e) transportation. For individuals who use AAC, communication, above all others, is necessary to maintain health and ensure independence through self-determination while gaining support from others within a safe environment.

Emergency/Disaster Preparedness and AAC

Efforts have been made to understand the unique vocabulary and communication needs that may arise during emergencies or disasters (Bryen, 2009). These efforts have resulted in a number of downloadable nonelectronic communication systems in the form of visual-graphic images and text for both people who use AAC and for first responders and shelter personnel (Bryen, 2009). Although these efforts are important and necessary, individuals who use AAC have a range of communication support needs. Although some individuals who use AAC are able to use predetermined vocabulary boards with novel pictures and text, others may find these boards challenging if they are very different from the communication system that they use day to day. Preparedness activities that are person centered, and account for the different kinds of communication support needs, both for comprehension and expression, are therefore extremely important to ensure the safety of individuals who use AAC if faced with an emergency or disaster.

A person-centered emergency/disaster preparedness model is described by Villeneuve (2019) that includes a strength-based approach to identifying, through self-assessment, targeted actions and advocacy relevant to the support needs an individual might have during an emergency. A person-centered preparedness workbook was developed that includes eight important elements to consider when engaging in person-centered planning (Villeneuve et al., 2020). The first of these elements is communication, and importantly identifies AAC modalities. It is important to consider the individual's current communication abilities and the kinds of symbols that a person who uses AAC comprehends and is able to use in expression if needed during an emergency/disaster

situation, so that those materials are the ones that are readily available.

Material planning is a component of preparedness described by Quinn and Stuart (2010). An important component of person-centered planning during preparedness activities may include laminated communication boards and written instructions on the best ways that the individual who uses AAC communicates using those boards. In addition to these materials, other materials such as medical records, medication needs, at least 7 days' worth of supplies for an individual's medical needs and alternate power sources for electronic AAC systems or other durable medical equipment are noted as important considerations. Quinn and Stuart also identify the importance of personal networking and community research around specific organizations to contact if and when an emergency or disaster happens and suggest meeting with local first responders, so they are aware of the specific needs an individual who uses AAC may have.

Given the unique needs of individuals who use AAC to both prepare for and access services if faced with a natural disaster or emergency, United States Society for Augmentative and Alternative Communication (USSAAC) formed a disaster relief committee (DRC) during 2005 in response to Hurricane Katrina and has since developed and disseminated materials and information that meets preparedness and potential support needs. Boesch et al. (2022) surveyed 13 families of individuals who use AAC who survived Hurricane Harvey in 2017 to understand their preparedness before, during, and after the hurricane and flooding that displaced residents of Texas and Louisiana. All participants felt that preparedness was important, but only one reported that they were prepared for Hurricane Harvey and most did not include AAC needs in their preparedness plan. Lost or damaged communication systems, anxiety due to disruption in their daily routines, and the use of temporary housing or shelters were reported as key impacts on the ability of the individual who uses AAC to communicate in the aftermath. Families also reported that access to lost/damaged items, transportation, and AAC-related supports would have been helpful in the immediate days that followed. As a result of these findings, USSAAC's DRC developed a number of emergency/disaster preparedness initiatives that included a text message–based toolkit.

The toolkit, *Disaster Preparedness for People Who Use AAC* (USSAAC, n.d.), is a learning tool aimed at assisting individuals who use AAC and their families to prepare for an emergency/disaster and specifically addresses issues related to communication. The toolkit delivers daily tasks, suggestions, and sample plans to prepare for communication needs if faced with a wide range of emergencies/disasters. These activities are completed over the course of 7 days at no cost. These messages are delivered directly to a mobile device that can receive Short Message Service (SMS) text messages or messages using WhatsApp, a free cross-platform messaging app. Each message contains a maximum of 1,200 characters and is based on a platform by Arist Holdings (2022). It is designed so that individuals who use AAC may complete activities of the toolkit on their own, using an asynchronous, microlearning approach; however, they are encouraged to select an "emergency/disaster partner" who also signs up for the toolkit and supports them if and when an emergency or disaster were to occur. A key outcome of the toolkit is that individuals who use AAC and their families know specific actions they can take in the event of an emergency/disaster, with access to communication being a priority.

Although communication was one of the five areas in a function-based approach to preparedness (Kailes & Lollar, 2021), few preparedness plans include communication supports and strategies for individuals with disabilities. Communication is needed to develop a person-centered, strength-based approach to preparedness planning. The use of AAC may help individuals with limited speech to demonstrate their agency and make decisions that have a direct impact on their lives. The preparedness guidelines developed by FEMA and PHEP, along with other national and international organizations, have not addressed communication supports and strategies for individuals who use AAC. The toolkit developed by USSAAC targets person-centered communication supports and strategies.

Clinical Focus

This clinically focused pilot study was designed to understand the utility of USSAAC's emergency/disaster preparedness toolkit for supporting communication preparedness efforts with individuals who use AAC. Individuals who use AAC have a range of unique support needs that may require limited to no support to complete the toolkit or require extensive support to complete activities of the toolkit. Individuals who use AAC also have unique communication needs to prepare for if faced with an emergency or disaster. This clinically focused pilot study used a protocol of guided intervention sessions to support service delivery with two individuals who use AAC who required individualized supports to complete the activities of USSAAC's emergency/disaster preparedness toolkit.

Purpose of the Pilot Study

The purpose of this study is to describe the impacts, particularly on communication preparedness, when participating in person-centered guided intervention

sessions to complete the activities of USSAAC's emergency/disaster preparedness toolkit (USSAAC, n.d.). Qualitative methods are used to identify successes and barriers when completing activities of the toolkit, highlight individualized communication support needs required to complete the activities of the emergency/disaster preparedness toolkit, and determine whether completing the activities of the toolkit increased perceptions of preparedness, particularly around communication needs, for individuals who use AAC and their caregivers. Specifically, the research aims of this project are as follows:

1. Describe the experiences of two individuals who use AAC when completing guided person-centered intervention sessions focused on the activities of USSAAC's emergency/disaster preparedness toolkit. First, the preparedness of individuals who use AAC is described. Second, the impact of sessions focused on preparedness activities within the toolkit is described. Third, factors that impacted the support needs that individuals who use AAC needed to complete the toolkit are described.
2. Identify the extent to which completing guided person-centered intervention sessions focused on activities of USSAAC's emergency/disaster preparedness toolkit changed the perceived preparedness of participants.

We anticipated that individuals who use AAC and their caregivers would implement strategies for preparedness at home that were learned during completing activities in the toolkit, and individuals and their caregivers would increase perceptions of preparedness through guided, person-centered, intervention sessions.

Method

Qualitative methods of content analysis were used to identify and describe the experiences of the two participants in the study (Patton, 2015). Content that was analyzed included pre-intervention interviews conducted with each participant and their primary caregiver about their emergency/disaster preparedness prior to the study and subjective, objective, assessment, and plan (SOAP) notes that were taken during and after each intervention session. SOAP notes are a systematic method of clinical reporting used by speech-language pathologists (SLPs) to note subjective and objective progress toward goals of each session and provide a narrative that evaluates and plans for subsequent sessions based on this progress observed (Roth & Worthington, 2021). The research team consisted of faculty in the fields of communication science and disorders, special education, and AT.

Participants

Three groups of individuals: university students, individuals who use AAC, and the primary caregiver (the mother of each participant) of each individual who used AAC were recruited to participate. University student participants were four undergraduate students in speech-language pathology at a public university located in the Midwest region of the United States. Two adults who used AAC and their caregivers also participated. Each caregiver was the legal guardian and mother of each adult who used AAC; therefore, caregivers signed electronic consent forms for themselves and the adult who used AAC to participate. The adults who used AAC provided assent. All student participants signed electronic consent forms before participating. Pseudonyms for each participant who used AAC (Luke and Oliver) instead of their real names are reported in order to protect their identity. All phases of this study were overseen by the institutional review board (IRB) of the university of the first author, the IRB of record for this collaborative study.

Participants who used AAC. Luke was a 25-year-old male with severe spastic quadriplegic cerebral palsy, dystonia chorea, and had a lack of coordination and balance, which required him to use a powered wheelchair for mobility. Oliver was a 20-year-old male with autism spectrum disorder and co-existing diagnoses of unspecified anxiety, attention-deficit/hyperactivity disorder, temporal lobe epilepsy, and pseudobulbar affect disorder. The Vineland Adaptive Behavior Scales–Third Edition (Vineland-3; Sparrow et al., 2016) was completed with Luke and Oliver using the parent/caregiver interview form. The Vineland-3 is a standardized measure that evaluates an individual's ability to participate in activities of daily living that includes communication, management of personal and living needs, and interactions with others across their day compared to others the same age. The Vineland-3 was administered in order to describe the profiles of the participants across three specific domains of Communication, Daily Living Skills, and Socialization. Receptive and expressive communication skills are identified using the Vineland-3 and are an important consideration when identifying communication supports needed to both access activities of USSAAC's emergency/disaster preparedness toolkit and develop preparedness plans around access to communication should an emergency or disaster occur. Additionally, individuals who use AAC may have a range of support needs to access activities of daily living and interact in social situations. The Vineland-3 characterizes these abilities of the two participants and provides context for the person-centered planning that was done in this clinically focused pilot study. The Vineland-3 provides a standard score with a M of 100 and SD of 15 across each

domain of Communication, Daily Living Skills, and Socialization. Additionally, an overall adaptive behavior composite (ABC) score is determined from these subdomains. The Communication domain evaluates receptive language, expressive language, and written communication. The Daily Living Skills domain evaluates skills across personal (e.g., eating, dressing, hygiene, and health care), domestic (e.g., household tasks of food prep, cleaning, and maintenance), numeric (e.g., using numbers for understanding time and money), and community participation (e.g., navigating travel outside the home, safety, and responsibility). The Socialization domain evaluates skills across areas of interpersonal relationships (e.g., relating to others, friendships, and conversation), play and leisure (e.g., engaging in activities with others), and coping (e.g., behavioral and emotional regulation across contexts).

Table 1 reports Luke and Oliver's scores across each of the Communication subdomains and domains of Daily Living Skills and Socialization. Vineland-3 ABC scores are reported in the final column of Table 1. It should be noted that Luke's support needs due to the motor impacts of cerebral palsy may have influenced his Vineland-3 scores, particularly in the Daily Living Skills domain. His primary mode of communication was a speech-generating AAC system with eye gaze access. His mother was present during all teletherapy sessions as his primary caregiver. Oliver primarily communicated by using a speech-generating AAC system with touch access using a dynamic display touchscreen. His mother was also present during all teletherapy sessions as his primary caregiver.

Student speech-language pathology clinicians. Four undergraduate students enrolled in a speech-language pathology program (all female, three were White, and one was Native American) between 20 and 22 years of age also participated. These student clinicians completed USSAAC's emergency/disaster preparedness toolkit independently prior to supporting the study. Students completed the course independently to prepare them to work directly with individuals who used AAC to access these activities and complete individualized intervention sessions during the next phase of the pilot study. Each student clinician was supervised by a clinical educator from the university in which the study took place during all phases of intervention planning, support, and documentation of SOAP notes.

Recruitment

To recruit individuals who use AAC, the authors sent recruitment flyers to clinic supervisors at their respective universities' speech and hearing clinic, community-based SLPs, USSAAC's Facebook page, one of the university clinics' Facebook page, and to the American Speech-Language-Hearing Association Special Interest Group 12: Augmentative and Alternative Communication discussion forum. Given that the authors used snowball sampling procedures to recruit individuals who use AAC, a response rate could not be calculated; however, these recruitment efforts resulted in the response of Luke and Oliver—the two participants in this study.recruit the student participants, e-mails were sent to students taking courses at the authors' respective universities. The e-mails included a brief statement about the purpose of the study, requirements for participation, and how to contact the authors to request more information or to express their interest in participating in the study. E-mails were sent to 247 students, with 26 students consenting, yielding an initial response rate of 9.5%. The four student participants in this study were chosen to work with Luke and Oliver, because they were from the same university clinic.

Inclusion Criteria

Student participants were required to be speech-language pathology or special education students in a master's or undergraduate program to be included in the study. For participants who used AAC, they were required to have a communication need that required the use of AAC and be able to participate in at least seven teletherapy sessions lasting approximately 1 hr each.

Materials

The authors created a set of pre-intervention interview questions for this study to understand preparedness efforts of Luke, Oliver, and their primary caregivers prior to participating in the study. These questions served as initial prompts for the student clinicians to elicit responses on the participants' disaster preparedness. The authors also developed an intervention guide for person-centered planning around the activities presented in the text-based toolkit previously created by USSAAC's DRC (USSAAC, n.d.) for the intervention portion of the study. This toolkit is freely available at https://arist.app/orgs/ussaac/courses/53606054-df1e-46c7-bc58-848481d22832. The toolkit consists of seven text messages delivered daily across 1 week of activities for participants to complete. Table 2 provides a description of how these activities were distributed across the 7 weeks of the study and completed within the context of specific goals and objectives created for Luke and Oliver. This intervention guide was used for person-centered planning each week around the specific toolkit activity or activities noted.

Procedure

Data Collection

Two student clinicians were each assigned to Luke and Oliver to lead teletherapy sessions. Teletherapy was

Table 1. Participant information.

Participant	Age	Gender	Diagnosis	Vineland Adaptive Behavior Scales–Third Edition						
				Receptive language v-scale score *M* = 10 *SD* = 3	Expressive language v-scale score *M* = 10 *SD* = 3	Written language v-scale score *M* = 10 *SD* = 3	Communication SS *M* = 100 *SD* = 15	Daily living skills SS *M* = 100 *SD* = 15	Socialization SS *M* = 100 *SD* = 15	ABC SS *M* = 100 *SD* = 15
Luke	25	Male	Spastic quadriplegia cerebral palsy	11	11	5	54	29	69	56
Oliver	20	Male	Autism spectrum disorder	4	8	6	48	69	64	63

Note. SS = standard score; ABC = adaptive behavior composite.

Table 2. Intervention guide and clinical procedures for person-centered planning.

LTG[a]	**Improve communication in an emergency or disaster with familiar and unfamiliar communication partners**
STGs[b]	• Client or caregiver will inform a familiar and an unfamiliar communication partner about their emergency communication profile (linguistic and strategic competence). • Client or caregiver will complete and share the communication profile with a familiar and unfamiliar communication partner (linguistic and strategic competence). • Client or caregiver will participate in creation of a nonelectronic communication board for use in emergencies and use that board to communicate needed messages in at least three situations with a familiar and unfamiliar communication partner (linguistic and operational competence). • Client or caregiver will demonstrate understanding of the need for an emergency preparedness plan and identify at least one person who needs to know the plan (strategic and social competence).
Session #	Objective(s) and activities
1	Objectives
	• The client and caregiver will complete consent/assent and begin the Vineland Scales of Adaptive Behavior–Third Edition (Vineland-3).
	Activities
	Consent/assent. Administration of Vineland-3.
2	Objectives
	• The client and caregiver will complete the Vineland-3. • The client and caregiver will participate in an interview about their emergency/disaster preparedness.
	Activities
	Administration of Vineland-3. Record qualitative interview with participant/family regarding preparedness.
3	Objectives
	• The client or caregiver will complete the personal emergency profile, as evidenced by the client or caregiver sharing the completed profile with the clinician. • The client or caregiver will complete Emergency Passport Notes (if the client/caregiver has a phone), as evidenced by the client or caregiver showing the clinician the notes page on their phone. • The client or caregiver will download the Red Cross app, as evidenced by the client or caregiver showing the app to the clinician.
	Activities
	Complete toolkit activities Days 1 and 2: Complete the personal emergency profile and communication passport: Accident and emergency PDF forms; help family download and explore Red Cross app.
4	Objectives
	• The client or caregiver will create an emergency low-tech communication board, with the support of the clinician and personalize as needed. • The client or caregiver will print out the personalized emergency communication board and practice using the communication board with the clinician.
	Activities
	Complete toolkit activities Days 3 and 4: Review, personalize, and print a nonelectronic emergency communication board; teach/review with family how to use notes apps on mobile device to store PDF documents and other information; role-play situations using the nonelectronic emergency communication board; discuss the concept of a "go bag" and needed items based on the participant.
5	Objectives
	• The client or caregiver will prepare and gather the items for the go bag with the assistance of the clinician. • The client or caregiver will complete the disaster preparedness (Emergency Checklist) form from toolkit activities Day 5 with the support of the clinician, print and put it in the notes page.
	Activities
	Complete toolkit activities Days 4 and 5: Prepare the "go bag" and where to keep it in the home; set reminders on participant's mobile device to update the "go bag" at least yearly; complete the Disaster Preparedness for People Who Have Limited Speech form," print a copy for the go bag, save an electronic copy in notes, and e-mail to a friend/family member.

(*table continues*)

Table 2. *(Continued).*

LTG[a]	Improve communication in an emergency or disaster with familiar and unfamiliar communication partners
6	Objectives
	• The client or caregiver will practice the emergency plan by role-playing with the clinician or other communication partner. • The client or caregiver will practice the emergency plan with a familiar communication partner (e.g., family, friends, and professionals), and report back to the clinicians at the next session.
	Activities
	Complete toolkit activities Day 6: Practice emergency plan with family; work with family to e-mail plan to up to three family members/friends and explain the plan to them; add their zip code in the Red Cross app and sign up for local emergency alerts; contact local police/fire departments to discuss client needs during an emergency; check FEMA's website to increase awareness of emergency services in the local area.
7	Objectives
	• The client will report the outcome of role-playing the emergency plan. • Client or caregiver will identify one community partner (e.g., EMS worker, teacher, shelter volunteers, and medical provider) that may provide support in the event of an emergency or disaster, inform that community partner of their plan, and practice their plan with them.
	Activities
	Complete toolkit activities Day 7: Review everything accomplished, thus far, address any outstanding items and make a plan to complete them; add USSAAC Recovers website to notes for easy access if needed; share a success story about preparedness and recovery with participant.

Note. FEMA = Federal Emergency Management Agency; EMS = emergency medical service; USSAAC = United States Society for Augmentative and Alternative Communication.

[a]Long-term goal. [b]Short-term goals.

chosen as the preferred format for sessions for personal health safety reasons due to the ongoing COVID-19 pandemic at the time that this study was conducted. Prior to teletherapy sessions, Luke, Oliver, and their caregivers participated in an interview to understand their experience with emergency/disaster preparedness. Interview questions (see the Appendix) centered on questions about their perspective and prior participation in emergency/disaster preparedness courses. Interview questions also asked if they currently have a plan that considers access to communication and if their current AAC system has vocabulary specific to emergency/disaster communication needs. Finally, the interview questions asked if they know about community resources available during an emergency/disaster. Interviews were conducted separately with Luke and his caregiver and Oliver and his caregiver and were audio- and video-recorded via Zoom.

Next, the student clinicians used the goals and objectives provided in Table 2 to design clinical session activities (also listed in Table 2) that follow the activities in USSAAC's 7-day toolkit, *Disaster Preparedness for People Who Use AAC*. The fifth author was a clinical educator at the university where the pilot study took place and provided supervision and support to the student clinicians as needed to ensure Luke, Oliver, and their caregivers received the necessary information about each component of the text-based toolkit course. Student clinicians were directed to preplan all teletherapy session activities to maximize the information delivered to the participants who used AAC. After each teletherapy session, the student clinicians and the fifth co-author completed SOAP notes to document progress during the teletherapy sessions (see Supplemental Material S1 for an example). SOAP notes provided narrative information that documented Luke, Oliver, and their caregiver's engagement and communication during the session, support needed to complete each activity within the session, progress toward session goals, barriers to completing the activities, and the activities planned for the next session based on their progress.

Data Analysis

Data were analyzed using thematic analysis of transcribed participant interviews conducted prior to intervention on preparedness, and the student clinicians' written SOAP notes following the teletherapy sessions, to recognize recurrent themes and repeated patterns of meanings related to the primary aims of this study (Patton, 2015). SOAP notes in this study were used not only to track participant progress and data in a traditional method but also as a reflection on the session and the toolkit activities with each participant. This reflective data in the SOAP sections was written in narrative form and suitable for qualitative data analysis. The supervising clinician and fifth author that supported completion of the SOAP notes did not participate in the initial rounds of thematic analysis with the research team. Utilizing a thematic analysis allowed for relationships between meanings to be identified from the interviews with the participants and their caregivers (Davidson & McAllister, 2002). Themes were identified around the primary aims of (a) describing preparedness for emergencies/

disasters, experiences using person-centered planning to complete activities of the toolkit, and factors that impacted the level of support needed to complete these activities and (b) the perceived level of preparedness of participants after completing guided sessions.

Audio and video transcripts of pre-intervention interviews were transcribed by two research assistants. One research assistant independently viewed the audio and video and created a transcript of the interview. A second research assistant checked the transcript for accuracy using the audio and video recordings. Any disagreements were discussed with the first research assistant, and consensus on the correct transcription was met.

Transcripts were next uploaded into Dedoose (2021; Version 9.0.17) for thematic analysis. Dedoose is a specialized software program for analyzing qualitative and mixed methods research and allows for organizing text into researcher-specified thematic categories. Written SOAP notes from each session from both participants were also uploaded into Dedoose for thematic analysis. Two researchers (third and fourth authors) individually reviewed the transcripts and SOAP notes and coded each theme that emerged. Each researcher initially developed themes individually using inductive methods where themes emerged from the data. After these themes were identified separately, the two members of the research team met to determine consensus and create operational definitions of themes that emerged using confirming and disconfirming evidence from the transcribed interviews and SOAP notes.

Six themes and 20 subthemes resulted. The entire research team met to determine consensus on the grouping of the themes and subthemes, resulting in one theme "awareness of needs" and "preparedness" being combined into one theme that expressed quotes describing the "awareness of need and preparedness" of the participants prior to intervention. Table 3 reports the final five themes and 18 subthemes with operational definitions that emerged.

Results

Using methods of qualitative content analysis described above, five themes and 18 subthemes emerged from (a) the video and audio transcripts from the pre-intervention interviews with Luke, Oliver, and their caregivers and (b) the SOAP notes from each intervention session. First, these themes and subthemes provided information about the nature of the participant's awareness of needs for preparedness, barriers to preparedness, and any preparedness efforts that were taken prior to participating. Second, these themes and subthemes captured the experiences of Luke, Oliver, and their caregivers when completing activities of the toolkit, so that factors that impacted the level of support needed to complete these activities could be realized. Finally, the perceived level of preparedness of participants after completing guided sessions was captured. Each of these themes and subthemes are defined in Table 3 and reported below to answer the primary aims of the study—describe the pre-intervention preparedness, experiences completing the toolkit, and outcomes for preparedness for Luke and Oliver.

Pre-intervention Preparedness

Awareness of Needs and Preparedness

Luke, Oliver, and their caregivers shared information regarding their level of awareness and preparedness efforts for an emergency or disaster prior to intervention. Five subthemes emerged: (a) need for/no emergency/disaster plan, (b) lack of needed vocabulary for an emergency/disaster, (c) lack of knowledge and resources, (d) preparedness efforts, and (e) work with agencies.

Subtheme 1: Need for/no emergency/disaster plan. Caregivers and participants acknowledged the need for an emergency/disaster plan or that they had no emergency/disaster plan in place. Participants stated that they may have thought about what could happen in the event of an emergency/disaster but had not yet developed a plan. When asked specifically about awareness of communication needs in an emergency/disaster, Oliver's caregiver responded, "Only vaguely... I know of the Red Cross and they would be someone to reach out to, but I don't have their numbers saved." Both participants acknowledged the need for an emergency/disaster plan and expressed concern that they did not have one.

Subtheme 2: Lack of needed vocabulary for an emergency/disaster. Both participants recognized that there was a lack of relevant vocabulary on their respective speech-generating AAC systems. One participant created a page on their speech-generating AAC system but had not considered a nonelectronic or low-tech communication board. For example, Oliver's caregiver said "... it [AAC speech generating AAC system] might have a few words ... I don't know that we have a screen or a page dedicated to that [emergency/disaster related messaging] ... I see it might be beneficial for us to set that up."

Subtheme 3: Lack of knowledge and resources. Quotes were identified that revealed participants' lack of knowledge and resources related to emergency/disaster preparedness. Both participants indicated that they had limited or no knowledge about emergency/disaster preparedness or how to obtain that information. When asked who they may contact in the event of a disaster or emergency, Luke's caregiver said, "... the fire department or local sheriff.

Table 3. Theme and subtheme definitions.

Theme	Subthemes and definitions
Awareness of needs and preparedness	Need for/no emergency plan: Participants indicated that they realized the need for an emergency plan for their loved one who uses AAC.
	Lack of vocabulary for emergency/disaster: Participants recognized the lack of vocabulary on the AAC speech-generating device.
	Lack of knowledge/resources: Participants indicated that they have limited to no knowledge about emergency planning or how to gather/obtain information.
	Preparedness: Participants indicated their level of preparedness for an emergency or disaster by stating actions they had taken, thought about, or that they did not feel prepared at all.
	Work with agencies: Participants noted the importance of working with local agencies, so there was an awareness of the individuals needs in the event of an emergency or disaster.
Barriers in emergency situations	Difficulty using speech: Participants had difficulty independently expressing concerns and needs in the event of an emergency or disaster.
	Outdated vocabulary and information: Participants recognized the lack of vocabulary on the AAC speech-generating device, as well as no additional low tech communication boards or options for communication. Caregivers acknowledged a lack of knowledge and skills regarding how to use an AAC device, how to program or how to use it with their loved one.
Challenges completing the toolkit	Health: Health concerns are an issue and a barrier, as health issues and caretaking will take priority over planning for an emergency or disaster.
	Technical issues: Caregivers had difficulty with downloading PDF's and creating files.
Actions during and after sessions	Personalize emergency communication board: Participants created low-tech AAC boards.
	Gather to go bag items: Participants prepared a go bag of items needed in the event of an emergency or disaster.
	Active participation during the session: Participants actively participate in the therapy sessions to ensure an understanding emergency preparedness.
	Practice in role play for an emergency/disaster: Participants practiced and participated in role-playing emergency scenarios. Participants indicated they needed to practice, participate, and prepare for an emergency.
	Scheduled a visit with emergency agencies: Participants prepared and planned visits with local fire and police.
	Suggestions during the session: Participants were willing to participate in the sessions and follow through with the suggestions. Recognizing the importance to their loved one.
Perspective about toolkit activities	Benefits of the toolkit study: Participants agreed it was a good idea to participate in the toolkit study, recognizing the need for an emergency plan.
	Importance of preparedness: Participants demonstrated an understanding of the importance of being prepared for an emergency or disaster situation.
	Planning for the future: Participants recognized that they needed to plan for the future in the event of an emergency or disaster.

Note. AAC = augmentative and alternative communication.

Maybe perhaps someone at the county board of DD [developmental disabilities]."

Subtheme 4: Preparedness efforts. Caregivers indicated their level of preparedness by either stating actions that they had taken, thought about, or that they did not feel prepared at all. For example, Luke's caregiver shared with the clinicians about a hospital stay where she made several large picture cards, coated them with packing tape, and put them around his bed where he would look toward the message. Aside from this example, both caregivers of participants indicated that they had thought about an emergency plan; however, they had not acted on establishing a plan; therefore, they did not feel well prepared should an emergency/disaster arise.

Subtheme 5: Work with agencies. Luke and Oliver's caregivers noted the importance of working with local agencies to both inform them about their needs in the event of an emergency/disaster and for Luke and Oliver to understand where to seek support if needed. For example, one participant stated: "We haven't really worked with them [local agencies] at all. We've worked with them; you know in the past for just different reasons."

Barriers in Emergency/Disaster Situations

Various barriers to communication were another theme that was found. Two subthemes emerged: (a) difficulty using speech and (b) outdated vocabulary and information.

Subtheme 1: Difficulty using speech. In the event of an emergency or disaster, Luke, Oliver, and/or their caregiver expressed concerns that they would not be an effective communicator without the presence of a caregiver. Luke's caregiver stated, "That's why I've been really focused on getting him communicating with his device so that his needs and wants and just whatever his words are going to be understood by people who are not familiar with him."

Subtheme 2: Outdated vocabulary and information. Luke, Oliver, or their caregivers discussed the need to learn more about how to use their speech-generating AAC systems, the need to review vocabulary, and a need to learn how to program and regularly update necessary vocabulary. For example, Luke's caregiver stated:

> *There is some vocabulary on there [speech generating AAC system]. I'm pretty certain there's not enough or the right, you know, words or phrases. Maybe we need something that has like a phrase or something on it, instead of just the different words.*

Toolkit Implementation Sessions

Challenges Completing the Toolkit

Some challenges were noted for Luke and Oliver when completing activities of the toolkit. Two subthemes emerged: (a) health and (b) technical issues.

Subtheme 1: Health. Luke had multiple medical support needs. Although these medical issues were stable at the time of the study, he fatigued easily. His ability to engage for extended periods of time with activities of the toolkit was difficult some days. His caregiver noted one day that "due to the time of the session [5pm] Luke became fatigued at the end of the session." More broadly, his family had concerns regarding the management of his health conditions, suggesting that the reasons they had not yet engaged in the toolkit activities were due to their other responsibilities focused on supporting his health. The immediate needs of his day-to-day health and wellness were implied to take priority over future planning for emergencies or disasters. For example, his mother stated, "I mean he's a complicated dude and he has a lot of needs and if it's—if I'm not able to do it you know, he's in a bad place."

Subtheme 2: Technical issues. Luke's and Oliver's caregivers expressed having some technical difficulties in using the toolkit. For example, Luke's caregiver said that she "... Attempted to complete the fillable PDF forms but encountered technical issues." In addition, she said, "I thought I saved them on my iPad, but when I opened them again, no information was saved."

Actions During and After Sessions

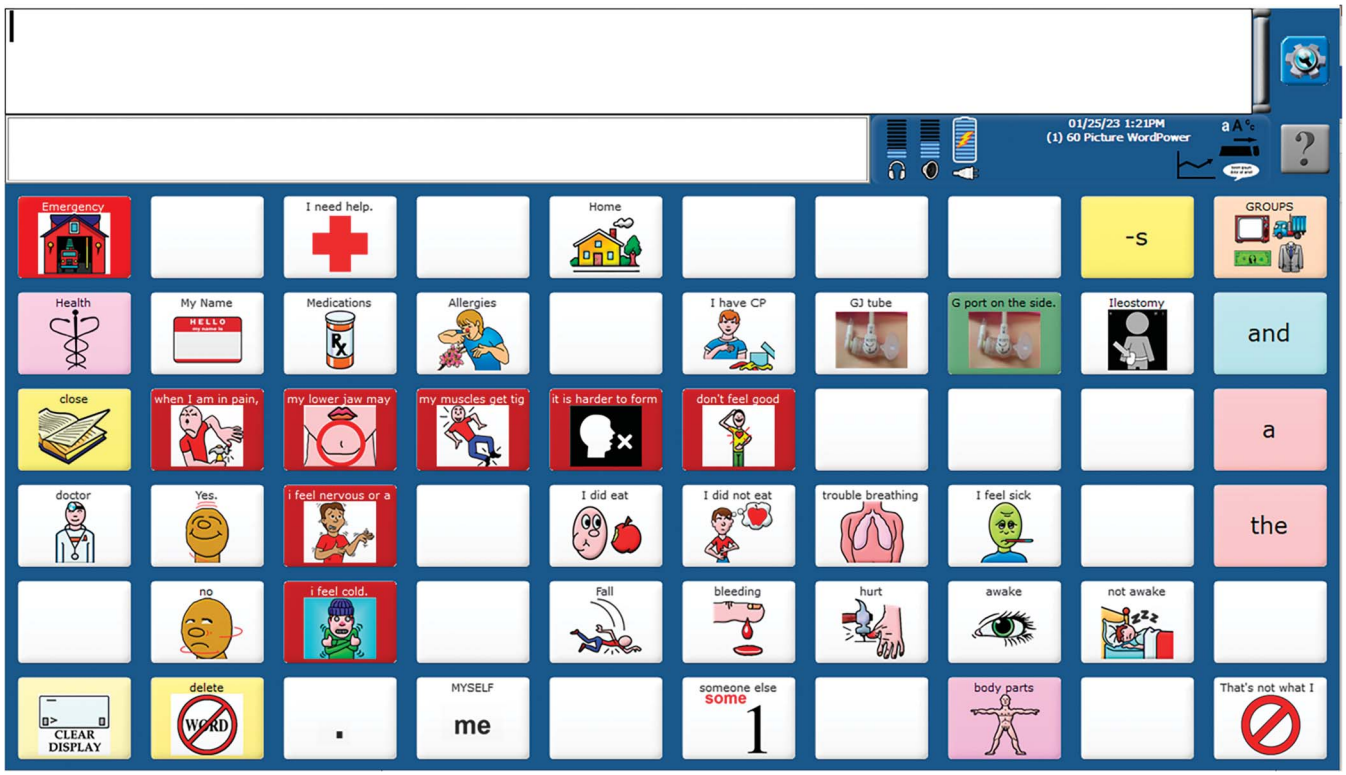
Six subthemes emerged that described the experiences of person-centered planning for completing the toolkit: (a) personalized emergency/disaster communication board, (b) gather to go bag items, (c) active participation during the session, (d) practice in role play for an emergency/disaster, (e) scheduled a visit with emergency agencies, and (f) suggestions during the session.

Subtheme 1: Personalized emergency/disaster communication board. Luke and Oliver created personalized nonelectronic communication boards. Student clinicians supported the participants to complete activities of the toolkit that guided thinking around additional vocabulary and personal information that may be needed in the event of an emergency/disaster. Figures 1 and 2 illustrate the personalized emergency/disaster communication boards created by each participant. These boards were developed together with the student clinician, supervising SLP, and caregiver in the session. Luke's communication board was created on his speech-generating AAC device. He and his family printed out a nonelectronic hard copy of this page to be used in the event that his speech-generating AAC device was unavailable. Using the same layout of symbols and words on this nonelectronic board ensured consistency across both of his systems. The communication passport activity within the toolkit provided the participant an opportunity to elaborate on the medical needs identified in his personalized communication board and to ensure that first responders and emergency workers had access to information that was critical to supporting his care if needed. Oliver also created a nonelectronic communication board for use in emergency/disaster scenarios to complement his speech-generating AAC device.

Subtheme 2: Gather go bag items. Luke and Oliver prepared a go bag of items needed in the event of an emergency/disaster. For example, Oliver's caregiver stated, "They have established his Go Bag at both my home and at dad's home." Both participants ensured that their nonelectronic communication boards were available in each go bag. Due to Luke having a gastrostomy tube (g-tube) and unable to eat by mouth, his mother specifically discussed how having the appropriate nutrition for Luke would be a challenge for the go bag given the unique nature of the formula needed for g-tube feeding and the limited places it is available.

Subtheme 3: Active participation during the session. Luke, Oliver, and their caregivers actively participated in the therapy sessions to ensure an understanding of emergency/disaster preparedness. For example, Luke's caregiver stated, "I downloaded it [Red Cross App] on my phone and me and Luke explored the features." She commented that, prior to the session, she did not realize how the Red Cross app could be helpful. Participants also

Figure 1. Luke's emergency communication board with names and identifying information removed.



completed a communication passport and personal emergency profile. Luke had complex medical needs, and he and his family worked on completing the profile over several weeks to ensure that it was complete, but succinct.

Subtheme 4: Practice in role play for an emergency/disaster. Luke and Oliver practiced and participated in role-playing emergency scenarios. Both participants indicated that they needed to practice, participate, and prepare for an emergency/disaster. For example, clinicians supported Luke and Oliver to role-play multiple emergency/disaster scenarios, including house fire, blizzard, flood, car crash, tornado, power outage, and family member medical emergencies. Practice included role-playing various scenarios using the emergency/disaster vocabulary on their nonelectronic communication boards and, for Luke, his speech-generating AAC device and the nonelectronic communication board.

Subtheme 5: Scheduled a visit with emergency agencies. Luke and Oliver prepared and planned visits with local fire and police departments. For example, Luke's caregiver scheduled a visit for herself and Luke to visit a local fire station so the firefighters could meet and familiarize themselves with Luke and his needs in case of an emergency/disaster. When scheduling the visit, the local emergency medical services (EMS) department representative stated that it would be beneficial to come to their home and assess how they could assist in the event of an emergency/disaster. When EMS personnel came to Luke's home, they worked with him and his family to create an "escape plan." They provided information to him and his family about where to put two identical go bags in the house to ensure that they would have the necessary supplies to evacuate through various exits in the home. Luke also practiced using his electronic and nonelectronic AAC systems to communicate with the local EMS providers. Oliver scheduled a visit to go to the local fire station; however, this visit occurred after the study concluded, so we do not have further information to report about his experience.

Subtheme 6: Suggestions during the session. Participants were willing to engage in the sessions and follow through with the suggestions embedded in the toolkit such as recognizing the importance of communicating the emergency/disaster plan with others. For example, Luke's caregiver reported that she attempted to use the "Notes" app on her iPad and phone but had some difficulty uploading the PDF documents. Alternative methods to store electronic documents were reviewed. Oliver's caregiver commented on the need not only to add emergency/disaster vocabulary but also to update other relevant personal information on his speech-

Figure 2. Oliver's emergency communication board with names and identifying information removed.

generating AAC system based on the content of the sessions. Throughout all sessions, clinical protocols were followed; however, student clinicians and the supervising SLP ensured that the participants' individual concerns were also addressed.

Impacts of Toolkit Sessions on Preparedness

Perspectives About Toolkit Activities

The participants and families shared their perspectives and reactions to activities within toolkit during and after the therapy sessions. Three subthemes emerged: (a) benefits of the toolkit study, (b) importance of preparedness, and (c) planning for the future.

Subtheme 1: Benefits of the toolkit study. Participants agreed that it was a good idea to participate in the toolkit study, because it increased their awareness of the need for an emergency/disaster plan and supported the creation of one that was personalized. For example, Oliver's caregiver stated, "This was a good study to participate in because it forced us to do that [prepare]and we'll be better off." Luke demonstrated active involvement in the sessions by independently naming people he wanted to educate about his emergency/disaster plan in the event that his primary caregiver was unavailable.

Subtheme 2: Importance of preparedness. Participants demonstrated an understanding of the importance of being prepared for an emergency/disaster situation. For example, Luke recognized that he did not have a way to independently call 911 for assistance if something were to happen to his mother. Although Oliver's caregiver stated, "I feel more confident and prepared to handle emergencies and his [Oliver's] communication abilities."

Subtheme 3: Planning for the future. After participating, caregivers and participants recognized that they needed to plan for potential emergencies/disasters. For example, Oliver's caregiver reported that she and her son's dad previously chose not to teach him to call 911 but are now considering a social story to help him understand

when it is appropriate to call 911. Luke's caregiver stated that they were also working to set up their home smart speaker to allow him to independently call for help when necessary, and that it was good to create a plan as well as have an ongoing strategy to update their emergency/disaster plan on a regular basis.

Discussion

Emergency/disaster preparedness for individuals who use AAC is critically important. This study highlights the need for preparedness activities that are person-centered and account for the individualized communication support needs of individuals who use AAC. Outcomes of this clinically focused work suggest that using these methods to complete the activities of USSAAC's disaster preparedness toolkit was feasible and supported positive change in perceived preparedness in the young adults who used AAC and their caregivers. Qualitative methods were used to identify experiences and outcomes when completing activities of the toolkit. Results highlighted the individualized support needs and actions that were taken by each participant, caregiver, student clinician, and supervising SLP to ensure the participants who used AAC felt prepared and able to communicate important messages, seek safety, and advocate for their needs if an emergency/disaster were to occur.

Prior to completing activities of the toolkit, participants and their caregivers expressed their need for an emergency plan, the lack of vocabulary readily available on their AAC system to communicate specific needs about an emergency/disaster, and their lack of knowledge about the components of a preparedness plan. Some of these results align with the findings from Boesch et al. (2022), where they surveyed families of individuals who use AAC. They reported that the families were all in agreement that it was important to have a disaster preparedness plan; yet, most did not create a plan to specifically address their AAC needs. Additionally, Boesch et al. reported that none of the families had practiced their plan despite being directly impacted by Hurricane Harvey, where their family member's AAC system was either lost or damaged.

In this study, it was evident in the discussions with Luke, Oliver, and their caregivers that, prior to completing activities of the toolkit, they were aware of their vulnerability in the event of an emergency/disaster and wanted to learn how to best prepare for such an event. Each participant and their caregiver knew that they needed to prepare but were unsure of where to start. This finding is not surprising. In a large-scale survey conducted by the United Nations Office for Disaster Risk Reduction (2013), they found that almost three-quarters of the 5,450 respondents did not have a disaster preparedness plan. Furthermore, many were not aware of their community's disaster management plan nor had they been asked to give input despite half of the respondents having a desire to engage in the disaster management plan. The findings from this study provide a context to understand the extent of the preparedness needs of each participant. It also highlights the importance of supporting individuals who use AAC when developing a disaster preparedness plan and in creating an individualized communication system to support their ability to advocate for themselves.

For both participants, important vocabulary, symbols, and/or messaging was lacking on their AAC systems, which limited their ability to communicate about specific medical needs (e.g., g-tube port placement and specialized nutrition needs), feelings, or contact information for caregivers. Given these limitations in their AAC systems, it also created barriers for communicating with first responders or other unfamiliar communication partners who may provide support during an emergency or disaster. The United Nations General Assembly (2006) stipulates measures be taken that consider, plan for, and meet the needs of individuals with disabilities during emergencies/disasters to ensure the inclusivity of this vulnerable population. Likewise, it is equally important for professionals who support individuals with disabilities that impact communication (e.g., those with AAC needs) to assist them and their families in planning for emergency/disaster events (Raja & Narasimhan, 2013). For Luke and Oliver, they used a speech-generating AAC device as their primary method of communication; however, neither participant had access to a nonelectronic communication board in the event that their electronic AAC system was inaccessible. Completing guided activities of the toolkit allowed for person-centered discussions with Luke, Oliver, and their caregivers to plan where to add this vocabulary, ensure comprehension of how and when to use it, and create a nonelectronic version of these messages for use if needed.

Luke, Oliver, and their caregivers noted the benefits of participating in focused therapy sessions targeting emergency/disaster preparedness. It was helpful for each caregiver and participant to have a specific time set aside to develop personalized emergency/disaster communication boards with relevant vocabulary and practice using the vocabulary on their AAC systems. Participants also prepared a go bag containing emergency/disaster-related items and engaged in role-playing scenarios that centered around emergency and disaster preparedness. Given the use of person-centered planning, these focused sessions were instrumental in assisting Luke, Oliver, and their caregivers in assessing their individualized communication needs. Equally as important, these sessions prompted the participants and their caregivers to engage with first responders within their local community to create

awareness of these communication needs, an activity that they would not have identified and engaged with before participating in this study. Additionally, Oliver's caregiver made plans to teach him how to call 911, and Luke planned to set up accessible home technology to call first responders during emergencies/disasters.

Limitations and Future Directions

Findings from this clinically focused pilot work present limitations in generalizability, given the number of participants, demographics, and preparedness needs represented by Luke and Oliver and the telepractice format in which it was conducted. We included only two participants who used AAC and their primary caregivers. Future replications of this work should include more participants who use AAC and who have a range of support needs, regional needs related to natural disasters, and specific preparedness needs to best understand the impacts of person-centered communication planning using USSAAC's emergency/disaster preparedness toolkit. Doing so may identify an even greater number of themes that explain the impacts of such planning. Second, given that the study was conducted during the COVID-19 pandemic, the student clinicians interacted with the participants and their caregivers through telepractice sessions, as it was considered the safest option, particularly for individuals who had complex medical needs. Although there is literature supporting the practicality and benefits of using teletherapy for individuals who use AAC (Nader & Erickson, 2023), it is unclear if the participants and their caregivers would have benefitted more from in-person guidance, especially when technical difficulties arose when completing some parts of the toolkit.

Another limitation of the study pertained to the terms used to refer to specific preparedness needs. We learned through initial discussions and in working with Luke and Oliver to complete the activities of the toolkit that our definition of disaster and emergency is possibly too narrow. Luke's caregiver suggested that, for them, an emergency was any situation that created a barrier between him and access to his immediate group of primary caregivers (i.e., those that really know him). They expressed how difficult it would be for Luke to communicate effectively without their support. These emergency situations could occur as a result of Luke becoming lost or unexpectedly isolated within a community setting without access to appropriate supports.

Given the success that Luke and Oliver had in engaging local first responders and caregivers in this process, future work should explore the outcomes of caregiver and first responder training that is specific to the communication needs of individuals who use AAC. Current efforts are underway to ensure that first responders are receiving the necessary training to support the needs of individuals who use AAC during emergency and disaster events (Frick et al., 2019; Mankey & Rang, 2018). In addition to training first responders, it is equally important for professionals, who work with individuals who use AAC, to support their clients in emergency/disaster preparedness (Boesch et al., 2022).

Student speech-language pathology clinicians supported the person-centered experiences of Luke, Oliver, and their caregivers to complete the activities of the toolkit. This opportunity allowed students to gain knowledge about the unique needs of Luke and Oliver as well as their caregivers that has informed their practice moving forward about the need for emergency/disaster preparation. Fidelity of the toolkit's delivery was not a focus of this study but, instead, this study created a protocol for person-centered planning using USSAAC's emergency/disaster preparedness toolkit. Future work should engage more clinicians, provide in-service training on the need for preparedness specific to communication needs, and evaluate the fidelity of the application of the toolkit implementation guide that was created for this study.

Conclusions

This clinically focused pilot study provided an in-depth account of Luke, Oliver, and their caregiver's experiences with person-centered planning for emergency/disaster preparedness. It is important to note the need for an expanded number of participants to and the addition of quantitative methodology to further inform our findings. However, findings from this early stage work suggest a call to action for SLPs to support person-centered planning around the communication needs of individuals who use AAC, so that they can ensure that the needs of individuals who use AAC are met should a disaster or emergency arise. Additionally, our work highlights the need for continued engagement in preparedness that is specific to communication needs across local, state, and federal agencies for individuals who use AAC. Our work with Luke, Oliver, and their caregivers highlights the role that access to communication, above all, is necessary to advocate for themselves and their needs during a time of crisis.

Data Availability Statement

The data analyzed are available from the corresponding author on reasonable request.

Acknowledgments

The authors would like to thank the two participants and their families for their participation in this study. The authors also would like to acknowledge the nearly 2 decades of work that United States Society for Augmentative and Alternative Communication's Disaster Relief Committee has done to develop the resources, materials, and text-based toolkit used for person-centered planning in this study.

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Appendix

Pre-Intervention Disaster/Emergency Preparedness Interview Questions

(1) Prior to agreeing to be part of this study, have you ever considered the need for incorporating disaster preparedness measures (e.g., having extra clothes packed, a backup communication board, and medication lists) to be sure you (or the person you support who uses AAC) can communicate in the event of an emergency?

If yes, tell me more about what you have considered.

(2) Have you ever participated in a training or course in emergency/disaster preparedness before? If yes, what kind of course was it?

(3) Do you or your family have a plan in place for how you would access existing AAC systems (e.g., speech-generating device, communication book or board, paper, and pencil) and/or assistive devices (e.g., hearing aids, wheelchairs, and walkers) in an emergency/disaster?

If yes, what have you done already to prepare?

(4) Does your current AAC system include access to vocabulary to be used during an emergency/disaster situation?

If yes, how comfortable are you using it?

(5) Do you know of specific agencies and/or resources in your community that are available to you during an emergency/disaster?

If yes, what are they?