

# Advancing Preparedness for Life Support Users During Power Outages

- Eric Cote, Founder
   Power Outage Partners
- Lisa Peterson, MPH, MPA, CPH, Senior Director Preparedness, ASTHO
- Adrianna Evans, MPH, Director
   Preparedness and Disability Integration, ASTHO
- Maggie Nilz, MPH, CPH, Senior Analyst
   Preparedness and Disability Integration, ASTHO

Thank you to the Louisiana Department of Health for their support and interest in this work.



This report was funded by the Centers for Disease Control and Prevention, under grant number NU380T000290. The findings and conclusions in this document are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the Department of Health and Human Services, or the other organizations involved, nor does the mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

### **Table of Contents**

Background: Addressing Power Outage Threats for Life Support Users
Chapter 1: Overview of Existing Strategies to Support Life Support and Durable Medical Equipment Users  During Power Outages
Chapter 2: Assessing New Options for Keeping Life Support Users Safe During Power Outages
• Level 1—Basic Impactful Activities
Level 2—Significant Activities with Increasing Impact
Level 3—Major Activities with Far-Reaching Impact
Chapter 3: Conducting a Feasibility Assessment
Step 1—Assess Interest Among Jurisdiction Senior Leadership
Step 2—Determine Availability of Staff/Consultant Support and Funding
Chapter 4: Finalize and Document the Action Plan, then Launch and Sustain the Program
Step 1—Fine Tune Project Scope Based on Available Resources
Step 2—Finalize and Develop a Written Action Plan
• Step 3—Hold a Stakeholder Meeting to Ensure Alignment on Action Plan and Responsibilities 20
Step 4—Launch and Sustain the Program
Conclusion
Appendix A: Tutorial on Battery Options When Extending Run Time for Ventilator Users
Appendix B: Table of Commonly Used Ventilators and Battery Options to Extend Run Time
<b>Appendix C</b> : Overview of State Medicaid Self-Direction Programs as a Resource for Funding the Purchase of External Batteries for Life Support Devices

### Background: Addressing Power Outage Threats for Life Support Users

For the average person, power outages are inconvenient. For the growing number of people who depend on life support devices and other electric-powered medical equipment in their homes, even short-term outages can become a matter of life and death, especially when outages occur with little warning.

The increased frequency and duration of power outages caused by natural disasters, documented in a Climate Central <u>report</u>, compounds the challenges faced by medical device users. In California, utilities implement intentional public safety power shutoffs (PSPS) to minimize the risk of wildfires sparked by utility lines. According to the <u>California Public Utilities Commission</u>, 78 PSPS events occurred between 2019 and 2022 in California.

Absent a reliable source of backup power, many people who depend on life support and other types of durable medical equipment (DME) rely on hospital emergency departments or emergency shelters during an outage, simply seeking a place to plug in their device. Power outages triggered by Hurricane Sandy in 2012 sent hundreds of DME users to hospital emergency departments to plug in their devices. The 2021 Texas power grid failure triggered more than 50 calls over a two-day period to an ambulance provider from patients with life-sustaining medical devices and no power.

The increased number of power outages requires new solutions to minimize risk to medical device users and reduce drain on hospitals, ambulance providers, and shelters during emergencies.



A wildfire burns near utility transmission lines in Southern California.



Damage from Hurricane Laura, which struck Louisiana in August 2020.

#### **Power Outage Partners**

<u>Power Outage Partners</u> is a pilot project launched in July 2021 by the Louisiana Department of Health (LDH) with funding, technical, and project management support from ASTHO. This initiative provides individuals using life support devices with additional external batteries that can significantly extend device runtime, affording additional time for evacuation that could prove lifesaving. For short outages, these batteries may avert the need for evacuation altogether.

The pilot is targeting invasively ventilated Louisianans for its initial support, given their need for 24/7 access to power. Power Outage Partners is proactively identifying and engaging invasively ventilated people to help ensure the highest possible participation in this first-of-its-kind program.

Louisiana hopes the pilot program's early success can pave the way for an expanded program that offers additional battery capacity for other life support users, including people who use oxygen, a group that constitutes 72% of Louisiana's electricity-dependent Medicare population.<sup>1</sup>

The Power Outage Partners pilot dovetails with two projects in New Orleans, including one that has equipped 15 government facilities with manual transfer switches that allow the facilities to rapidly connect to a commercial-scale portable generator during an outage. Another project seeks to establish 85 resiliency hubs at churches and community centers where commercial-scale solar power and backup battery capacity would maintain power during outages. The two projects can provide locations where life support and DME users could have prioritized access to recharge medical device batteries.

# Chapter 1: Existing Strategies for Life Support and Durable Medical Equipment Users During Power Outages

The toolkit makes numerous references to life support devices and electric-powered durable medical equipment (DME). Although life support devices are examples of electric-powered DME, they differ, as life support devices must generally be used 24/7. Examples of life support devices include ventilators, stationary oxygen concentrators, and ventricular assist devices. When the term DME is used in this toolkit, it refers to electric-powered durable medical equipment.

The power outage challenges facing those who depend on life support and other DME equipment have spawned a range of strategies, detailed below.

#### **Jurisdiction Registries**

Many states and localities have established special needs registries that enable life support and DME users to voluntarily self-report where they live, the types of electric-powered medical devices they use, and any special assistance they might need during a disaster or power outage. Registries can help officials prioritize evacuation support for people with disabilities and identify people who may need wellness checks during a power outage.

#### **Utility Programs**

Many utilities maintain programs that enable customers who depend on electric-powered medical devices to voluntarily register themselves on utility lists. Utilities use these lists to provide advanced notification to a medical device user anytime planned maintenance work will trigger a temporary outage and to ensure that no medical device user loses power due to non-payment. A small number of utilities provide rate discounts to medical device users. Some municipal-run utilities and rural electric cooperatives, which traditionally have far fewer customers than larger utilities, can prioritize power restoration for medical device users.

One of the most innovative approaches to addressing the power outage needs of people who use electric-powered medical devices comes from California's three largest investor-owned utilities: Pacific Gas & Electric, Southern California Edison, and San Diego Gas & Electric. In 2019 and 2020, these utilities launched programs like the Power Outage Partners pilot initiative that provide life support and DME users at risk of PSPS events with portable battery systems that can operate a number of electric-powered medical devices. Since their start, these programs have invested over \$30 million to provide battery systems to over 20,000 Californians.<sup>2</sup>

<sup>&</sup>lt;sup>1</sup>Based on emPOWER data reported in February 2022.

<sup>&</sup>lt;sup>2</sup> This information was developed through research conducted by the author, including data review from the California Public Utilities Commission website, discussions with battery manufacturers supplying batteries to California utilities, and figures from <a href="Pacific Gas & Electric">Pacific Gas & Electric</a>, and <a href="Southern California Edison">Southern California Edison</a>.

#### emPOWER Program

Heeding the lessons of Hurricane Sandy and previous disasters, in 2013 HHS began developing its <a href="mailto:emPOWER">emPOWER</a> program to help government officials, hospitals, and shelter operators better anticipate the potential surge of electricity-dependent Medicare beneficiaries during a power outage. emPOWER regularly reports current data to state and local public health officials on the number of Medicare beneficiaries using one or more of 14 types of electric-powered medical devices.

HHS has since expanded emPOWER to allow authorized state health department officials to request an emergency outreach dataset, a list of the names and addresses of DME users that HHS releases to enable life-saving outreach during a disaster. Many jurisdictions across the country have used these lists to evacuate Medicare beneficiaries who rely on DME during power outages as well as those under threat from wildfires and flooding.

#### **Other Solutions**

Medical professionals, academics, and disability advocates have also been on the front lines trying to develop better solutions to address the problems power outages pose to electricity-dependent patients. Some medical professionals have advocated for improvements in government support for DME users during power outages and <a href="stressed">stressed</a> the importance of ensuring local emergency officials know how many people who use power-dependent devices might have to be rescued. Others have <a href="proposed">proposed</a> more research and data collection to better identify the number of people facing these threats. Other recommendations include government incentives to encourage DME users to purchase and maintain their own backup power solutions.

# Chapter 2: Assessing New Options for Keeping Life Support Users Safe During Power Outages

Jurisdictions can use this toolkit to explore a range of options for keeping life support users safe during power outages, including initiatives modeled after the Power Outage Partners pilot and more modest approaches that can still prove beneficial. This toolkit categorizes suggested activities across these three levels of intensity:

- Level 1—Basic Impactful Activities
- Level 2—Significant Activities with Increasing Impact
- Level 3—Major Activities with Far-Reaching Impact

#### Level 1—Basic Impactful Activities

Three basic, beneficial activities a jurisdiction can undertake to help DME users during power outages include:

- Assess current efforts and available resources for DME users during power outages and evaluate opportunities to increase support.
- Identify existing utility programs to support customers using DME and explore opportunities for collaboration between utilities and public health, emergency management, and disability affairs agencies.
- Initiate discussions with DME suppliers to assess opportunities for collaboration.

#### Assessing Current Efforts and Available Resources

#### Quick Reference Code L1A

Most jurisdictions have undertaken some level of work to assist people who use electricity-dependent medical devices during power outages. Conducting a thorough assessment of this work will help identify areas where additional effort can make a meaningful impact. During

this assessment, input from both officials in charge of providing services for individuals with disabilities and from disability advocacy groups will be essential to identifying service gaps. It is also critical to identify available funding sources that DME users can tap to purchase additional batteries for their medical device. Since Medicare and Medicaid generally do not pay for external batteries for DME, check to determine if the jurisdiction has any Medicaid waiver programs or other funding sources that provide funding for DME batteries.

Next, determine which agencies are receiving periodic emPOWER reports from HHS on the latest number of Medicare beneficiaries using DME. Determine what actions, if any, the jurisdiction is currently taking as a result of these reports. This would also help to determine whether emPOWER data is being regularly shared with hospitals and parties responsible for operating disaster shelters, which could improve coordination.

Jurisdictions may find it helpful to determine whether they have ever requested an emPOWER emergency outreach data set and, if so, under what circumstances. If the jurisdiction has never requested an emergency outreach dataset, confer with public health preparedness colleagues and emergency management officials to discuss how access to this dataset could enhance response activities during a disaster.

(An ASTHOBrief on emPOWER includes additional information on how to effectively use this valuable resource.)

### **User Friendly Summary Table and Quick Reference Codes**

Table 3 summarizes each potential activity detailed in Chapter 2, the planning steps outlined in Chapter 3, and implementation actions detailed in Chapter 4. The table also provides an estimate of the required personnel and financial resources for each activity, step, or action. Estimates for the required range of hours for activities are

based on the experience of staff and the project consultant for the Power Outage Partners pilot in Louisiana. Therefore, actual hours required in other jurisdictions could vary considerably. The table also provides guidance on how to allocate responsibility among the project team members for each activity. Descriptions of potential activities, planning steps and implementation actions include quick reference codes hyperlinked to the table to make it easier for toolkit readers to quickly move back and forth between suggested activities, planning steps, or implementation actions, and associated resource requirements. Note: Quick reference codes for suggested activities begin with the letter L, planning step codes begin with the letter P and implementation action codes begin with the letter I. Activities that must be undertaken before subsequent activities are launched are identified as prerequisite activities.

### Identifying and Evaluating Utility Programs to Support Life Support Equipment Users

#### Quick Reference Code L1B

Many utilities maintain medical baseline programs that enable customers who use electric-powered medical devices to voluntarily register themselves on utility lists. If a jurisdiction learns that its electric utilities offer these programs, they can connect with utilities to explore opportunities for collaboration.

These medical baseline programs may include only a fraction of a jurisdiction's actual DME users. Jurisdictions may be able to help boost enrollment in these utility programs by promoting them through existing communications channels and relationships with key stakeholders. In jurisdictions where utilities have a program to support DME users and government agencies maintain a special needs registry, it may be helpful to compare these lists to identify individuals who may be on one list but not the other.

# Initiating Discussions with Durable Medical Equipment Suppliers to Assess Opportunities for Collaboration

#### Quick Reference Code L1C

Close coordination between Power Outage Partners and DME suppliers yielded important information about the types of ventilators used in Louisiana and the source of health insurance for ventilator users. Later sections of the toolkit detail how this data helped support Louisiana's Power Outage Partners pilot.

Discussions with DME suppliers also shed light on their efforts to support DME users during power outages. These conversations highlighted new ways government agencies could collaborate with DME suppliers to collectively enhance support for DME users during outages. One DME supplier offered to deliver emergency power equipment to its customers prior to anticipated outages if government agencies provided the equipment.

Two national trade associations representing home medical providers and DME suppliers collectively represent thousands of providers across the country. These groups include the <a href="Home Care Association of America">Home Care Association of America</a> and the <a href="American Association for Home Care">America</a> and the <a href="American Association for Home Care">American Association for Home Care</a>. They have chapters in many states that can connect jurisdictions with local members for discussions about how to collectively support DME users.

### Level 2—Significant Activities with Increasing Impact

More significant activities that can meaningfully enhance support for DME users include:

- Quantifying the number of life support and DME users living in the jurisdiction, including the most at-risk individuals, based on the type of device used (e.g., invasive ventilator, stationary oxygen concentrator).
- Quantify backup power resources for life support users.
- Recruit owners of standby residential generators to help recharge batteries during an outage.

### Quantifying the Number of Durable Medical Equipment Users Living in the Jurisdiction by Device Type

#### Quick Reference Code L2A

Quantifying the number of DME users living in a jurisdiction by device type will give health agencies, emergency managers, hospital administrators, and disaster shelter operators a clearer sense of how many people may show up at a hospital or shelter during an outage seeking to plug in their electricity-dependent device. These people are likely to be using portable devices, such as ventilators, portable oxygen concentrators, and bilevel positive airway pressure machines.

Stakeholders can begin to quantify the number of DME users living in a jurisdiction by reviewing HHS emPOWER data, which details the number of Medicare beneficiaries relying on one or more of the 14 types of electric-powered medical devices. Since emPOWER data does not include Medicaid beneficiaries who are not dually eligible for Medicare or those individuals covered by private insurance, jurisdictions will need to do additional research to get the full picture of the number of DME users.

Jurisdictions can work with Medicaid officials to request reports on the number of DME users by device type using the 14 types of devices captured in emPOWER data. Medicaid officials may find this process easier for some devices since the number of billing codes associated with medical devices varies considerably. In several cases, multiple billing codes exist for the services required by someone using a medical device and are different than the billing code for the device itself. Medicaid officials should be able to distinguish between service codes and device codes to provide an accurate count of DME users by device type. A senior official in the health agency leading or supporting the initiative can make the request for this Medicaid data to help expedite the process.

Obtaining information about the number of DME users covered by private health insurance may prove more challenging. A health agency leader can ask insurance companies to produce de-identified reports on the number of life support users by device type using billing codes. Jurisdictions can also consider asking their insurance commissioner to make this request.

### Using Louisiana's Approach to Determine the Population of Invasively Ventilated Citizens



Since Louisiana's Power Outage Partners pilot prioritized its initial funding to purchase batteries for invasively ventilated individuals, given their need for 24/7 access to power, the state needed to gather and analyze additional data to distinguish between invasively ventilated and non-invasively ventilated Louisianans. This process not only helps determine the size of each group but also enable cost projections for equipping all invasively ventilated Louisianans with additional battery capacity.

To obtain the breakdown between types of ventilation, a request was made of Louisiana's Medicaid officials for a de-identified report detailing the number of Medicaid beneficiaries associated with the billing codes for the three types of ventilation: invasive ventilation (E0465), non-invasive ventilation (E0466), and multifunction ventilation with suction and other support functions (E0467). <u>Table 1</u> details the 2022 Louisiana ventilator Medicaid data with the breakdown for type of ventilation among the 1,634 beneficiaries.

Since emPOWER data does not distinguish between type of ventilation, Louisiana developed projections for ventilation types among Medicare beneficiaries by extrapolating the breakdown of ventilator type among Medicaid beneficiaries (see <u>Table 2</u>). This data Power Outage Partners received from Louisiana's Medicaid officials on the type of ventilation among beneficiaries included information on the Medicaid beneficiaries who were also eligible for Medicare, known as dual eligible individuals. Dual eligible individuals were subtracted from the projected number of invasively ventilated Medicare beneficiaries to avoid double counting them.

Table 1: Louisiana Ventilator Medicaid Data

Types of Ventilation	Allocation Medicaid Beneficiaries	Percentage
Invasively Ventilated	207	12.66%
Non-Invasively Ventilated	1,424	87.15%
Multifunction Ventilation	3	0.183%
Totals	1,634	100%

### Table 2: Projections for Invasive and Non-Invasive Ventilation in Louisiana

Type of Ventilation	Confirmed allocation of 2022 Louisiana Medicaid beneficiaries by type of ventilation, with the number of dually eligible individuals in parentheses followed by the percentage of ventilation type among the total population.	Projected allocation of ventilation type among Medicare beneficiaries (determined by multiplying the known percentage of the Medicaid population by ventilation type against the known population of 2,688 ventilated Medicare beneficiaries and subtracting dually eligible individuals).	Projected number of privately insured invasively ventilated individuals (determined by multiplying the percentage of privately insured individuals among the sample populations of 107 invasively ventilated Louisianans (19.6%) and 122 non-ventilated Louisianans (29.5%).	Totals
Invasive Ventilation	207 (32 dually eligible individuals), 12.66%	2,688 x .1266 = 340 - 32 = 308	207 x .196 = 40 + 308 x .196 = 60 Total 100	207 + 308 + 100 = 615
Noninvasive Ventilation	1,424 (524 dually eligible individuals), 87.15%	2,688 x .8715 = 2,343 - 524 = 1,819	1,819 x .295 = 536	1,424 + 1,819 + 536 = 3,779
Multifunction Ventilation	3 (0 dually eligible individuals) .183%	2,688 x .00183 = 5	Unknown	3 + 5 = 8
Totals	1,634	2,132		4,402

<sup>&</sup>lt;sup>3</sup> This data was provided by the Louisiana Department of Health.

<sup>&</sup>lt;sup>4</sup> This information is based on emPOWER data.

<sup>&</sup>lt;sup>5</sup> This data was provided by DME suppliers.

### **Quantifying Backup Power Resources for Life Support Users**

#### Quick Reference Code L2B

Some jurisdictions may intend to provide funding to life support and DME users to extend device run time but may not currently have the funding in place to begin providing support. Jurisdictions in these scenarios can still consider gathering important information about the backup power resources currently available to DME users, as this information will enable jurisdictions to prioritize support for those with the fewest resources.

The best sources of information about invasively ventilated individuals will be DME suppliers and case management firms that help coordinate care and support resources for these patients. Louisiana's experience working with DME suppliers provides helpful guidance for this process. Three DME suppliers in Louisiana provided de-identified data on 138 invasively ventilated Louisianans, including the type of device used and amount of backup battery run time for each device.

Initiative leaders extrapolated this data to project the market share of specific ventilator models across the estimated population of invasively ventilated Louisianas covered by Medicaid, Medicare, and private insurance. This calculation enabled officials to see the expected number of individuals using the two oldest ventilator models that offer the least amount of internal battery run time, the LTV 1150 and Trilogy 100, which provide 1 hour, and 3 hours of internal battery run time, respectively.

DME suppliers also provided information about the additional battery resources they provided to the LTV 1150 and Trilogy 100 users, at their own expense, to extend device run time during an outage. These resources generally consisted of a 12-volt marine battery that provided an additional 8 to 10 hours of run time. Knowing the combined internal and external battery run time for invasively ventilated individuals will help Louisiana prioritize initial support for those

with the least amount of run time. See <u>Table 4</u> for information about ventilator market share and details on battery solutions to extend ventilator run time.

#### **Recommended Best Practice:**

A jurisdiction that plans to provide funding to extend battery run time for DME users can enlist its state's regulatory agency overseeing DME suppliers and health agencies overseeing case management firms to officially request data on individual DME users. This data should be obtained and stored in a manner that adheres to HIPAA guidelines. Suggested data to obtain for ventilator patients includes specific ventilator models, type of ventilation (invasive vs. noninvasive), number and type of external batteries, and the source of the patient's health insurance. For oxygen patients, suggested data to obtain includes number of liters of oxygen used per minute, type of oxygen concentrators in the home, number of oxygen tanks on hand, and source of the patient's health insurance.

### Recruiting Owners of Standby Residential Generators to Help Recharge Batteries During an Outage

#### Quick Reference Code L2C

Jurisdictions can consider recruiting owners of standby residential generators to help life support users recharge batteries during an outage. Unlike a portable generator, a standby residential generator is permanently installed by a licensed professional and turns on automatically when the power goes out. Reliance on this type of generator can eliminate problems associated with the misuse of portable generators. A CDC report on Hurricane lan's impact attributed 16 deaths to carbon monoxide poisoning from misuse of portable generators, which occurs when the generators are placed too close to a home's windows and doorways, allowing the deadly, odorless, and colorless carbon monoxide produced by generators to seep into the home.

The first step in leveraging standby generators is to develop a list of residential generator owners. Since

installing standby residential generators generally requires a building permit, jurisdictions can likely obtain this data through public record requests. Once identified, jurisdictions can begin to recruit generator owners to recharge their neighbors' life support equipment batteries.

Leveraging geographic information system technology allows jurisdictions to map the locations of participating generator owners and life support users seeking assistance to determine the ratio of donors to recipients in various locations. Given the cost of standby residential generators, it is likely that low-income areas have fewer generator owners. To promote equity for life support users in these areas, jurisdictions may need to boost recruitment of nearby generator owners in low-income areas.

A force of credentialed volunteers or public safety employees could be recruited to transport depleted batteries between life support users and standby generator owners before returning recharged batteries to the user. This approach protects the privacy of life support users and generator owners by eliminating the need for these groups to interact. This approach also minimizes the challenges generator owners and life support users may face to personally shuttle depleted and recharged batteries to and from households.

While recruiting this volunteer force can be a logistical challenge, some jurisdictions maintain lists of individuals willing to volunteer during disasters who could be asked to help with battery transport. Partnering with local public health or emergency management agencies can help to identify a trained workforce that may also be able to transport batteries.

Another option would be for jurisdictions to designate a government facility as a drop off and pick up location where depleted batteries could be brought for recharging and returned once recharged by generator owners. This approach would function much like the <a href="mailto:oxygen bottle">oxygen bottle</a> exchange program LDH operates.

(Important safety caution: It would be unsafe for a life support user with only one external battery for their device to provide that battery to a recharging source during an outage. This would leave the person with no battery capacity beyond what internal battery capacity their device might have until their recharged external battery is returned. Given this challenge, life support users with multiple external batteries would be the only individuals who could safely take advantage of a battery recharging program.)

### **Documenting the Number of Standby Residential Owners in Louisiana**



As part of the Power Outage Partners pilot, LDH identified over 6,000 owners of standby residential generators, including 4,600 in Baton Rouge and 1,500 in New Orleans, through public records requests submitted to

building permit offices in these cities seeking the names and addresses of all permit holders on record.

### Level 3—Major Activities with Far-Reaching Impact

Jurisdictions that undertake Level 1 and Level 2 activities and have identified funding to boost power outage support for DME users will be positioned to launch larger initiatives with far reaching impact. These initiatives include:

- Providing funding for life support users to purchase additional batteries to extend device run time. (This is the model that Louisiana's Power Outage Partners initiative and the program by California's utilities uses.)
- Investing in a cache of batteries for the most commonly used life support devices and/or universal battery systems that can charge various types of life support and DME devices.
- Establishing community recharging facilities with dedicated emergency power resources.

### Providing Funding to Life Support Users to Extend Device Run Time via Battery Systems

#### Quick Reference Code L3A

Jurisdictions with the resources to provide DME users with additional batteries to extend device run time will first need to decide how much funding they can invest. This decision will determine the number of DME users they can support. Suggested criteria to determine eligibility should include patient acuity, an approach that would likely prioritize invasively ventilated individuals and the most at-risk oxygen patients for initial support.

Determining which oxygen users are most at risk is significantly more challenging than distinguishing between people who are invasively and noninvasively ventilated. Invasive ventilation can be easily distinguished from non-invasive ventilation by unique billing codes. However, many oxygen concentrator users with varying degrees of acuity rely on the same devices, including stationary oxygen concentrators, portable oxygen concentrators and oxygen tanks. The best indicator of acuity among people using oxygen is the number of liters of oxygen consumed each minute. This data would best be obtained from physicians, but may also be available from DME suppliers, home healthcare agencies, and case management firms. Since people using oxygen represent the largest percentage of DME users, fulfilling this request for information could be a timeconsuming process.

Other potential criteria to determine eligibility for additional external batteries could include a person's use of multiple DME devices. In these cases, jurisdictions may wish to provide additional batteries or a larger battery system to extend run time for all devices, a move that would increase the cost of support for such a person. Other prioritization factors could be proximity to a nearby source of emergency power and limited evacuation resources. People who live farther away from these resources may have a greater need for battery power. This is

an important consideration to promote equity for people living in rural areas.

Jurisdictions may have other priorities based on the type of threats they face. For example, people who use electric-powered wheelchairs may face increased threats from flash floods or wildfires if they can't operate their wheelchair when evacuating. To the extent these threats are accompanied by power outages, ensuring that electric-powered wheelchair users have sufficient backup battery capacity may be a priority. Jurisdictions will need to decide which populations to prioritize based on their available

### Determine How to Securely Obtain and Store Data on Durable Medical Equipment Users

Jurisdictions that intend to provide funding to help DME users extend battery run time for their devices will need to decide how they plan to identify and reach these individuals. Then, they will need to securely store and track data on the funding and support services they provide. Creating a centralized database of DME users broken down by device type would simplify outreach and record keeping. Regardless of how jurisdictions maintain information on DME users who have received funding for additional batteries, jurisdictions should consider sharing this information with local emergency managers so they can incorporate it into evacuation planning. Consider a scenario in which evacuation resources are limited. To the extent first responders know that an invasively ventilated individual now has 24 hours of battery run time, first responders can prioritize assistance for someone facing a more immediate threat.

#### Louisiana's Approach to Securely Storing and Tracking Durable Medical Equipment User Data



In Louisiana, LDH's Bureau of Community Preparedness was the lead agency supporting the Power Outage Partners pilot. However, the bureau was not authorized to obtain personally identifiable data on people

who are invasively ventilated since the agency was not a direct service provider. However, two other LDH agencies—the Office of Citizens with Developmental Disabilities and the Office of Aging and Adult Services—are direct service providers. Since both agencies rely on data vendors to maintain personally identifiable data on Medicaid and Medicare beneficiaries, these vendors will be tapped to help document and track applications for funding from invasively ventilated beneficiaries. As funding is provided to Louisianans, project leaders from the Bureau of Community Preparedness will receive de-identified data on the number of individuals who received additional external batteries for life support devices.

### Documenting the Funding Application Process for Durable Medical Equipment Users

Jurisdictions that intend to provide funding to help DME users extend battery run time for their devices will each have their own process based on the source of funds and associated eligibility guidelines. Jurisdictions should develop clear and accessible communications tools to make the application and battery ordering process as easy to understand as possible. (See <a href="Appendix C">Appendix C</a> for information on Medicaid self-directed services as a potential source of funding to help DME users extend device run time.)

### Investing in a Cache of batteries for Life Support Devices and/or Universal Battery Systems

#### Quick Reference Code L3B

Jurisdictions may wish to consider investing in a cache of batteries suitable for the most commonly used ventilators or in non-device specific battery systems, such as those offered by California's utilities. (See Appendix A and Appendix B for information on battery considerations.) Jurisdictions could store fully charged batteries in a central location(s) to be distributed as needed during extended power outages. This approach would follow the model of Louisiana's Oxygen Bottle Exchange program, in which oxygen patients, or their family members and caregivers, can exchange empty oxygen tanks for full ones during power outages at designated government facilities located in every parish in Louisiana.

#### **Creating Community Charging Stations**

#### Quick Reference Code L3C

Jurisdictions could consider creating community charging stations supported by emergency generators where DME users could recharge batteries on a prioritized basis. In 2022, the City of New Orleans worked with its electric utility Entergy, which invested \$900,000 in rate payer funds for the Generator Readiness Program, which equips 15 government facilities with manual transfer switches to allow the city to rapidly connect a commercial-scale portable generator during an outage. Other recharging facilities in New Orleans with emergency power provided by commercial-scale solar power and battery storage systems are planned. Similar programs in other jurisdictions could become a source for prioritized battery recharging for DME users.

#### **Tips on Where to Find Funding**

Each of the suggested Level 3 activities requires significant funding. Good starting places to identify potential funding sources are a jurisdiction's Medicaid agency, its developmental disability council, and any assistive technology organizations, as these entities are likely responsible for overseeing services and programs for people with intellectual and developmental disabilities. Certain programs may offer funding for home care needs, such as DME equipment like external batteries, to help people live at home rather than in costly nursing home settings.

### **Louisiana Funding Sources Offer Guidance for Other Jurisdictions**



In Louisiana, LDH identified four funding sources they could use to purchase additional batteries, including three Medicaid Waiver programs: the Residential Options Waiver, the New Opportunities Waiver, and the Children's Choice Waiver.

Louisiana also identified Act 378 Individual and Family Support Program funds as a source non-Medicaid beneficiaries could tap to purchase additional backup batteries for their ventilators. These funding sources cover DME expenditures and provide some flexibility in allowing beneficiaries to allocate funds for equipment or services they deem necessary to live independently outside of a nursing home. This equipment can often include portable generators and battery systems that will extend run time for medical devices.

Unused federal or state disaster relief funds associated with recent disasters may also allow jurisdictions to purchase extra batteries. DME suppliers may be an alternative if government funding is unavailable.

As noted previously, California's largest investorowned utilities have invested over \$30 million since 2019 to equip more than 20,000 customers with battery systems to power medical devices during PSPS events, and Louisiana's Entergy invested \$900,000 to support the Generator Readiness Program. These investments establish a precedent for utilities to increase their investments of ratepayer funds that mitigate the impact of power outages on medical device users. Other jurisdictions can initiate discussions with utilities about the possibility of similar investments.

Another potential source of funds for additional investments may be the federal Infrastructure Investment and Jobs Act, which provides \$12 billion over a five-year period starting in 2022 for states and utilities to help mitigate the impact of power outages. State emergency management agencies are often the lead agencies working with their governors, and consulting with utilities, when deciding which projects will be submitted for funding under this act. Public health agencies can engage with their state emergency management agency and utilities to explore future applications for this funding to support programs that assist life support users during outages.

### Chapter 3: Conducting a Feasibility Assessment

After reviewing the range of potential activities, a feasibility assessment can determine which approach makes the most sense based on your jurisdiction's available resources. A jurisdiction's feasibility assessment should incorporate these two important steps:

- Step 1—Assess interest in the initiative among jurisdiction senior leadership.
- Step 2—Determine availability of staff/consultant support and funding.

### Step 1—Assess Interest in Initiative Among Jurisdiction Senior Leadership

#### Quick Reference Code P1

Senior leaders of a jurisdiction's health department and/or its disability affairs agency need to have a strong interest in and assume responsibility for supporting an initiative and securing the resources necessary to ensure success. Leaders that have initial interest can review this toolkit to familiarize themselves with suggested approaches and the resources required for each approach. If a non-governmental disability advocacy organization is spearheading this initiative, this organization will need to enlist the support of key government partners to move forward.

#### Step 2 – Determine Availability of Staff/Consultant Support and Funding

#### Quick Reference Code P2

The amount of personnel resources available to support a project will have a major bearing on what your jurisdiction can achieved. Projects will need a project manager to lead the activities. Project managers should be experienced professionals capable of planning and leading complex initiatives with support, as needed, from agency leadership. Depending on the scope of the work, project coordinators may also be needed. Project coordinators can be junior level personnel who can receive direction and support from either a project manager or an agency leader. A combination of existing personnel and consultants can fill these roles. Funding availability will also have a major bearing on what jurisdictions can accomplish. (Review the <u>Tips on Where to Find Funding</u> section above for more information.)

# Table 3—Summary Table of Suggested Activities, Planning Steps, and Implementation Actions with Estimated Personnel and Funding Requirements and Quick Reference Codes

Quick Reference Code for Suggested Activities	Level 1 Activities	Estimated Range of Hours	Suggested Allocation of Responsibility Among Team Members.
			Jurisdictions will find it helpful to identify individuals who can serve as a program coordinator, a project manager, and a senior agency leader who can help plan and implement an initiative. Agency leaders providing support for initiatives do not need to be cabinet secretaries but should be senior leaders capable of interacting with other agency leaders when coordination is necessary.

### ASTHO**Report**

L1A	Assess current efforts and available resources to support DME users during power outages, including HHS's emPOWER data, and evaluate opportunities to step up support. Prerequisite for Level 3A1, 3A2, and 3A3 activities.	20-40 hours	This will require engagement with several government and private sector stakeholders. Agency leadership can introduce this assessment process, via memo and/or meeting, to help stakeholders recognize the importance of the assessment. Program coordinators can assist with the research. In coordination with agency leadership, the project manager should evaluate the findings and develop recommendations on how to close any gaps.
L1B	Identify existing utility programs to support customers who use life support and other DME and explore opportunities for collaboration.	15-40 hours	A project coordinator can undertake initial work. It's best if agency leadership and the project manager initiate discussions with utilities about potential opportunities for collaboration, with follow-up coordination from the project manager.
L1C	Initiate discussions with DME suppliers to assess opportunities for collaboration. Prerequisite for L3A.	15-25 hours	A project manager is best suited to undertake this task. The project manager should report findings to agency leadership and enlist their help as needed to engage with DME suppliers.
	Level 2 Activities		
L2A	Quantify the number of DME users living in the jurisdiction, including the most at-risk people, based on the type of life support needed (e.g., invasive ventilation, highest levels of oxygen therapy).	30-50 hours	This is best led by the project manager. When it comes to engaging with the insurance industry to obtain de-identified data about privately insured life support and DME users, it is recommended that agency leadership initiate this outreach or enlist the support of a jurisdiction's insurance commissioner to help obtain needed information.

### ASTHO**Report**

L2B	Identify backup power resources for life support users to help prioritize assistance to those with the least amount of battery run time (should funding become available).	75-125 hours	This is best led by the project manager. The project manager will need to work closely with DME suppliers, home health agencies, and case management firms to obtain detailed information required to assess the amount of battery run time life support users currently have.
L2C	Recruit owners of standby residential generators to help recharge batteries during an outage, develop program guidelines, and implement the program.	75-200+ hours	Project managers should take the lead in developing and implementing this program, enlisting support from project coordinators and agency leaders as needed to help secure support from local building officials, emergency managers, and other stakeholders.
	Level 3 Activities		
L3A	Provide funding to life support users to purchase additional batteries to extend device run time, develop program guidelines, and implement the program.	200-300+ hours/high costs	Project managers should take the lead in developing and implementing a program to provide funding to life support users to purchase additional batteries. Agency leadership should be actively involved, especially to make decisions about individuals' program eligibility. If project coordinators are available, they can provide support. Given the significant costs involved, coordination between agency leadership and a jurisdiction's governor, mayor, or executive may be needed.
L3B	Invest in a cache of batteries for devices and/or universal battery systems and manage this program.	200-300+ hours/high costs	Project managers should take the lead in developing and implementing a program of this magnitude, working closely with agency leadership. Given the

### ASTHO**Report**

			significant costs involved, coordination between agency leadership and a jurisdiction's governor, mayor, or executive may be needed.
L3C	Establish community recharging facilities.	200-300+ hours/high costs	Project managers should take the lead in developing and implementing a program of this magnitude, working closely with agency leadership. Given the significant costs involved, coordination between agency leadership and a jurisdiction's governor, mayor, or executive may be needed.
	Planning Steps		
P1	Conduct a feasibility assessment that includes assessing interest in the initiative among senior leadership of the health department and/or disability affairs agency.	25-40 hours	Project managers should take the lead in discussing a potential initiative with agency leadership. Reviewing this toolkit can help agency leadership understand the level of resources needed for various activities.
P2	Identify and quantify available personnel resources and funding.	25-40 hours	The project manager should take the lead in identifying and quantifying available resources. Extra care should be given during this process to confirm with agency leadership that personnel and funding are available.
	Implementation Actions		
IA	Fine tune project scope based on available resources.	25-40 hours	Project managers should take the lead in fine the tuning project scope with input from agency leadership, paying careful attention to confirming available personnel and financial resources.

IB	Finalize and develop a written action plan.	25-40 hours	Project managers should finalize the action plan in close coordination with agency leadership and then develop a draft of the written action plan. This draft should be reviewed carefully by agency leadership, with a final draft developed by the project manager reflecting this input. Agency leadership should sign off on the final action plan.
IC	Hold a stakeholder meeting to ensure alignment on the action plan and responsibilities.	Varies based on agencies involved	Agency leaders should issue invitations to this meeting with logistics coordinated by the project manager. Agency leaders should lead discussion at the meeting in coordination with the project manager.
ID	Launch and sustain the program.	Varies based on selected approach	The project manager should take the lead in launching and sustaining the initiative while working closely with agency leadership as needed. Project coordinators can play an important role in this phase of the project, especially for more resource-intense initiatives.

### Chapter 4: Finalize and Document the Action Plan, then Launch and Sustain the Program

Following the feasibility assessment that confirms agency leadership commitment and quantifies available personnel and financial resources, jurisdictions can advance to the final planning and operational stage, which involves the following steps:

- Step 1—Fine Tune Project Scope Based on Available Resources
- Step 2—Finalize and Develop a Written Action Plan
- Step 3—Hold a Stakeholder Meeting to Ensure Alignment on Action Plan and Responsibilities
- Step 4—Launch and Sustain the Program

#### Step 1—Fine Tune Project Scope Based on Available Resources

#### Quick Reference Code IA

After confirming the personnel and financial resources available, jurisdictions can fine tune the scope of their initiative. If the jurisdiction has funding to extend device run time for DME users, project staff will need to determine the type and number of DME users receiving assistance and the amount of funding to be provided. Since these activities may be new for jurisdictions, it may be helpful to be flexible when establishing timelines for completing key milestones.

#### Step 2—Finalize and Develop a Written Action Plan

#### Quick Reference Code IB

The following steps will help jurisdictions finalize and develop a written action plan. (Further details on these steps are provided below.)

- Define roles and responsibilities of key stakeholders.
- Finalize and document the application and adjudication process (for jurisdictions providing funding for battery purchases).
- Develop a rollout and communications plan.
- Develop a post-launch sustainment plan.
- Document a detailed written action plan.

#### **Define Roles and Responsibilities of Key Stakeholders**

Jurisdictions need to engage all relevant stakeholders—including the disability community—to ensure the initiative's success. The action plan should detail the roles and responsibilities of key government agencies, disability advocacy organizations, DME suppliers, and any contractors supporting the project.

The success of Louisiana's Power Outage Partners initiative was due to the active engagement of many public and private sector stakeholders. These included:



- LDH Bureau of Community Preparedness
- LDH Office for Citizens with Developmental Disabilities
- LDH Office of Adult and Aging Services
- Louisiana Governor's Office of Disability Affairs
- Louisiana Developmental
   Disabilities Council

- Louisiana Statewide Independent Living Council
- Ventilator Assisted Care Network
- Trach Mommas of Louisiana
- Louisiana Community Provider Association
- Home Care Association of Louisiana
- Brain Injury Association of Louisiana
- Louisiana Chapter of the United Spinal Association

# Finalize and Document the Application and Adjudication Process (For Jurisdictions Providing Funding for Battery Purchases)

Accessing government funding to purchase external batteries for DME users can be a complex process. Your action plan should include a detailed, written description of the process DME users must follow to obtain funding. This description will ensure that government agencies and personnel are aware of the intricacies of the process and the roles of specific personnel or contractors in developing application forms, receiving applications, assisting applicants, reviewing and approving applications, and helping applicants obtain additional batteries for their life support and DME devices.

### Develop a Rollout and Communications Plan

The finalized action plan should spell out details for the program's launch that address logistics and communications. Key questions and considerations to address include:

- Will there be an event to officially launch the initiative? If so, who will take the lead in organizing the event?
- What accommodations for accessibility will you need to consider in all communication events and materials?
- Who can you identify as potential program champions to help promote the program, and what specific responsibilities should they be asked to undertake?

The communications component of the action plan should detail the tools and resources needed to effectively introduce the new program to key audiences. The plan should ensure coordinated communications among public and private sector organizations to maximize impact. All communications should account for accessibility. Your jurisdiction should communicate information to the

public via multiple platforms and formats to ensure information reaches the whole community, including those with disabilities and other access and functional needs. Accessible public information utilizes any or all of the following:

- Plain language
- Large print
- Braille
- Section 508-compatible digital media (including documents, presentations, websites, social media, etc.)
- Captioned video
- ASL interpreters
- Other language interpreters

The communications plan should include or address the following communications tools, resources, and timelines:

- The program background
- Instructional documents to guide DME users through any application process.
- Online or printed forms needed to apply for assistance.
- Press releases
- Instructional documents to guide DME users through any application process.
- Web content
- Social media assets
- A schedule detailing the timing and responsible party for each communications tactic.

#### Develop a Post-Launch Sustainment Plan

The detailed planning steps outlined in this toolkit aim to help you ensure a successful launch. However, to sustain a successful initiative over time, your jurisdiction should take the following critically important post-launch sustainment actions:

 Communicating early successes with all stakeholders to help build further interest in and sustain momentum for the program.

- Working with agency leaders to address any challenges that arise, including any unexpected program eligibility obstacles or questions.
- Checking in with agencies or contractors directly involved in receiving and adjudicating applications to monitor progress, documenting the number of applications, tracking the number of approved applications, and helping to troubleshoot any issues that arise.
- Making decisions about expanding or contracting the program based on the initial rate of applications and approvals and remaining resources.
- Engaging in policy discussions about necessary appropriations or regulatory changes needed to sustain or expand the program.

### **Document a Detailed Written Action Plan**

Once your jurisdiction decides to go forward with your initiative and you have completed the above final planning steps, your jurisdiction should develop a detailed, written action plan that captures the scope of the initiative and addresses key operational details. The complexity of the action plan will vary significantly based on the scope of your initiative. Key elements of the action plan should include:

- An executive summary.
- Overview of key stakeholder roles and responsibilities.
- A rollout plan that addresses announcement logistics and communications.
- A post-launch sustainment plan.

The following two components of the action plan are only relevant for Level 3 activities:

- Describe your sources and amounts of current funding.
- Document your application and adjudication process.

#### Step 3—Hold a Stakeholder Meeting to Ensure Alignment on Action Plan and Responsibilities

#### Quick Reference Code IC

During the preliminary feasibility assessment process, it is likely that leaders and senior staff of key agencies and disability advocacy organizations would have held preliminary planning discussions to weigh interest in an initiative and identify available resources. Your jurisdiction will now need to facilitate a much more detailed planning meeting among the leaders of these agencies, their staff, and any consultants who will be supporting the initiative prior to the launch. This meeting should be scheduled after you draft your jurisdiction's action plan. The primary focus of this meeting will be to review the action plan, address any needed modifications, and ensure that all stakeholders agree on the plan of action and their responsibilities in carrying out the plan.

### Step 4—Launch and Sustain the Program

#### Quick Reference Code ID

Following your program launch, it will be vitally important for agency leaders and project managers to provide sustained support by implementing the post-launch deliverables detailed above and any others that may arise. Documenting and showcasing success will be especially important in building support for the program's continuation, and expansion, as resources allow.

#### **Conclusion**

Resource limitations influence the services available to people with disabilities at every level of the U.S. healthcare system. The nation's largest private and public health insurance providers, including Medicaid and Medicare, generally do not pay for the external batteries that could extend run time for life-sustaining medical devices during a power outage.

As this toolkit has demonstrated, this approach forces many life support users to hospital emergency departments during outages simply to plug in their device. This uses limited resources at a time when hospitals themselves may be operating on emergency power and at reduced capacity. With the options laid out in this toolkit, jurisdictions can enable life support and DME users to safely shelter at home for longer periods of time. This both frees up limited hospital resources and provides additional safety and peace of mind for life support and DME users during emergencies.

In publishing this toolkit, ASTHO has aimed to provide a roadmap for how jurisdictions can improve their support for DME users during power outages, ranging from modest but beneficial actions to more resource-intensive programs like Louisiana's Power Outage Partners pilot. The more jurisdictions undertake this important work, the more much needed progress the country can make in boosting support for people using life support and DME devices during power outages.

# Appendix A: Tutorial on Battery Options When Extending Run Time for Ventilator Users

Project leaders for Louisiana's Power Outage
Partners pilot have gained valuable knowledge
about ventilators' capabilities and limitations
during power outages. This insight helped shape
Louisiana's approach to extending battery run time
for people who are invasively ventilated. To help
other jurisdictions benefit from Louisiana's
knowledge, Power Outage Partners have shared key
information below about ventilators and the battery
systems that operate them during outages.

All ventilators used in home settings are equipped with an internal battery that will operate the device during a power outage. The length of internal battery run time among the ventilators varies significantly,

with two widely used models, the LTV 1150 and the Trilogy 100, providing only one and three hours of run time, respectively. Newer models provide as much as 8 hours of run time. In addition to using the internal ventilator batteries, individuals can extend their ventilator run time with external batteries sold by the ventilator manufacturers or by other manufacturers.

Given the limited internal battery run time for the LTV 1150 and the Trilogy 100, DME suppliers in Louisiana indicated that they provide individuals using these devices with 12-volt marine batteries and an inverter kit, at their own expense, to provide an additional 8 or more hours of run time. Since insurers do not reimburse for external batteries, the less expensive 12-volt battery, when compared to the cost of external batteries offered by device manufacturers, is generally the preferred approach by DME suppliers.

Appendix B details the projected market share among the four most commonly used ventilator models in Louisiana based on data for 138 invasively ventilated Louisianans, the run time of each model's internal and external manufacturer batteries, and the cost for each ventilator's external battery provided by the device manufacturer. (The data includes the same information for the 12-volt marine battery.)

## Appendix B: Table of Commonly Used Ventilators and Battery Options to Extend Run Time

This table describes internal battery run times for commonly used ventilators, as well as the additional run time provided by external batteries sold by ventilator manufacturers. The table also includes the projected market share of these ventilators in Louisiana based on data provided by DME suppliers. The table also includes information on the cost of external batteries provided by the ventilator manufacturers and the commonly used 12-volt marine battery. This data was provided to the Power Outage Partners project manager by DME suppliers and ventilator manufacturers.

### Table 4: Internal and External Battery Run Times for Commonly Used Ventilators

Ventilator Type	Internal battery run time, number of projected users among estimated population of 615 invasively ventilated Louisianans, and percentage of market share.	Run time of external single or dual battery system developed by ventilator manufacturer with total run time for internal and external battery (or batteries) and cost of external battery or batteries. (Note: These manufacturer batteries are less than 5 pounds.)	Cost for 12-volt marine battery with inverter, run time in addition to internal battery, and battery weight.
LTV 1150	1 hour Users: 134 out of 615 21.8% of market	5 hours/6 hours (requires a two-pack battery system) \$1,300	\$450/8 hours Weight: 65 lbs.
Trilogy 100	3 hours Users: 312 out of 615 50.7% of market	3 hours/6 hours (single external battery) \$450	\$450/10 hours Weight: 65 lbs.
Trilogy EVO	8 hours Users: 138 out of 615 22.4% of market	8 hours/16 hours (can be equipped with two external batteries each with 8 hours of run time for total run time of 24 hours) \$550 per battery	\$450/10 hours Weight: 65 lbs.
Astral	8 hours Users: 31 out of 615 5% of market	8 hours/16 hours (can be equipped with two external batteries each with 8 hours of run time for total run time of 24 hours) \$\\$700 per battery\$	\$450/10 hours Weight: 65 lbs.

# Appendix C: Overview of State Medicaid Self-Direction Programs as a Resource for Funding the Purchase of External Batteries for Life Support Devices

Self-directed Medicaid services are services that participants—or their representatives, if applicable—have decision-making authority over and take direct responsibility of with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-directed services allow participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process.

Self-direction promotes personal choice and control over the delivery of waiver and state plan services, including who provides the services and how services are provided. For example, participants are afforded the decision-making authority to recruit, hire, train and supervise the individuals who furnish their services. The Centers for Medicare & Medicaid Services (CMS) calls this "employer authority." Participants may also have decision-making authority over how the Medicaid funds in a budget are spent. CMS refers to this as "budget authority." See Medicaid's website for more information about self-directed Medicaid services.

The Clean Energy Group's Home Health in the Dark Report cites Medicaid self-direction programs as a viable option that allows Medicaid beneficiaries to use a portion of their individual budgets to purchase (or lease if available) goods and services included in their approved individual plan, which would allow for a generator. The report cites Ohio as an example where eligible beneficiaries have received a home generator through the Ohio Home Care Waiver Program, which allowed a portion of their individual self-direction budget to be allocated toward installing a generator.

Self-direction services programs provide Medicaid beneficiaries with autonomy over their services and supports by allowing them to control a portion of their budget, including purchasing goods and services and hiring their own support workers. Creating flexible self-direction programs could be a unique way for states to begin accepting battery storage applications within pre-existing waiver programs.