

Easy Does It: A Promising Model for Emergency Home and Community-Based Services

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Introduction

Easy Does It (EDI), a non-profit organization founded by people with disabilities in 1994, provides emergency personal assistance services (PAS), accessible transportation, wheelchair and assistive device repair, case management and other services for people with physical disabilities who live in Berkeley, California. In 2018, with 26 employees and a \$1.2 million budget, EDI responded to 3,814 requests for service from about 600 disabled and older residents of Berkeley.¹ The organization exemplifies a promising practice for providing emergency PAS and other home and community-based services (HCBS) for people with significant functional limitations. This report introduces EDI and presents a basic blueprint for people advocating to provide similar services in their communities.

We report why and how EDI was established; describe the key program elements, along with annual service figures; outline the process for getting the agency funded; present staff and client perceptions of the role EDI services play in supporting disabled Berkeley residents' health, independence, personal choice, and safety; and discuss programmatic strengths and challenges in the context of changing local labor and housing markets from the perspectives of both administrative and direct services staff. We conclude with examples of certain federal Medicaid requirements for backup PAS as they compare with EDI services and recommend next steps for key stakeholders.

Background

In the early 1970s, disabled activists from Berkeley, California successfully advocated for state and county funding for PAS, which would allow them to live independently in communities of their choice rather than with their families, on whom they were dependent for care, or in restrictive institutions. Even as these newly funded services facilitated independence and autonomy for many over time, systemic service gaps also presented new barriers to successful community living.

One notable problem was the absence of emergency backup services when a PAS worker didn't show up for work or the disabled person had a care emergency when a regularly scheduled PAS worker wasn't available. If other PAS workers, family members, or friends were not available to assist, the person might miss a meal, be unable to get out of bed, not go to the toilet, or spend the night in their wheelchair until the morning worker arrived. Sometimes the person would be forced to call 911 for help. Such service gaps threatened their health and wellbeing and jeopardized living independently.

Initially, disabled people responded to this service gap by creating informal mechanisms for dealing with worker emergencies. For example, individuals within friendship networks shared PAS workers who were willing to fill in short-term when emergencies arose. As this practice became more established, disabled activists considered ways to formally structure these services, eventually leading to the creation of

¹ Source: interviews with EDI staff, 2018.

EDI's predecessor, Vantastic/Last Call, funded by the City of Berkeley in 1991.² Other early funding included private grants and community development block grant funds.

In 1998, Berkeley voters passed Measure E, a ballot initiative that levied a small property tax to pay for emergency personal care, wheelchair and adaptive equipment repair, and transportation for disabled Berkeley residents. Later, in 2000, Measure B, an Alameda County ballot measure provided funding so that EDI could provide additional transportation services for anyone eligible for paratransit.³ EDI also offered case management, primarily for newly disabled individuals who had little experience locating, hiring and supervising PAS workers. Recently, EDI received funding for community emergency preparedness planning and limited additional funding to support emergency services for people with mental health disabilities.

Program description

Services offered

Emergency personal assistance services

Emergency PAS are available 24 hours a day seven days a week. Workers are available to assist with activities such as transferring in and out of bed, bathing, dressing, feeding, and toileting. Workers can also perform other tasks such as cooking basic meals, grocery shopping, washing dishes, and paying bills. Emergency workers are available for a two-hour shift and can extend that time under certain circumstances. Typically two female and two male PAS workers are on call during peak shifts such as 7 AM to 11 AM, when demand is highest. Optimally, at least one male and one female PAS worker are scheduled during shifts when demand is lower, such as overnight.

Workers who are on call can wait in any location so long as they can reach a client within 45 minutes after being contacted by the dispatcher. A disabled person who needs emergency PAS telephones EDI's 24/7 dispatch number, which is prominently displayed on the organization's website and widely distributed locally to disability and senior groups and other service organizations. The dispatcher then contacts an on-call worker, who telephones the client to learn what they need and to provide an estimated time of arrival. EDI responded to 1,547 emergency PAS service calls during 2018.

Wheelchair and assistive technology repair

EDI also provides emergency repairs for assistive equipment such as manual and motorized wheelchairs, scooters, patient lifts, ramps, elevators, wheelchair van lifts, and adjustable beds. A skilled service technician was available approximately 10 hours per day, seven days a week, to make repairs at the person's home or where they have experienced a breakdown in the community. The organization maintains an extensive collection of donated or used wheelchairs and other parts that can either be used to fix a broken chair or other device or loaned to the person short-term at no cost while repairs are being done. EDI responded to 691 equipment repair service calls during 2018.

Transportation

EDI provides rides on request for routine trips for residents who have been found eligible for county paratransit services. It also provides rescue rides for emergencies for anyone within Berkeley. Paratransit eligibility is not required for rescue rides. Two lift-equipped vans transport clients within Berkeley or to destinations within a mile of the Berkeley border. Rides on request are available for any purpose weekdays 8 AM to midnight and weekends 10 AM to midnight. Rescue rides are available 24 hours a day seven days a week to

² Berkeley City Council Resolution No. 55,922 – N.S. Retrieved June 5, 2017 from City of Berkeley website, archived records online at <https://www.cityofberkeley.info/recordsonline/paFile/cqFiles/index.html>

³ Retrieved from <https://www.alamedactc.org/measureb> on April 16, 2019.

meet unforeseen transportation emergencies such as a broken wheelchair or a medical emergency. EDI provided a total of 1,576 rides during 2018.

Case management

The organization also provides limited case management. Typically, this service is offered when an individual is having persistent difficulty finding or retaining PAS workers or is newly disabled and does not have experience hiring, supervising, or managing workers. Most of these individuals have had a major change in their functional status or are older people who have just been discharged from the hospital or a rehabilitation center after a fall or recovery from a stroke.

The case manager helps the person recruit, screen, and hire PAS workers, and access other available disability services. They also guide the client through the steps required to manage and supervise a PAS worker and keep accurate time records. Effective PAS recruitment often relies on tapping into established personal networks and community connections in addition to simply advertising job openings, so EDI's long presence in the community facilitates identifying possible PAS workers. The organization reports providing case management to around 30 clients at any given time, including PAS hiring assistance for 10 to 15 of them. An average of six cases are closed monthly.

Supported independent living services

Supported independent living services are available for people who require more comprehensive assistance managing their PAS needs. Services include assistance with interviewing and hiring attendants, training and assistance in managing workers, help maintaining schedules and managing attendant funds, and help in obtaining funding to pay attendants. EDI provides supported independent living services for between 30 and 50 disabled people at any given time, including for some individuals who live outside the Berkeley area.

Staffing

During 2018, EDI employed a total of 26 full- and part-time staff. Twenty-one employees provided direct services and four held administrative or management roles. Direct service personnel included one outreach coordinator, five dispatchers, one case manager, nine PAS workers, four drivers and two wheelchair and equipment repair technicians.

Client fees

EDI clients pay a co-pay of \$15 per hour for core services including PAS, transportation, and wheelchair and equipment repair. The co-pay could be negotiated or waived when a client had a financial hardship. Supported living services are funded entirely by client fees and case management is provided free of charge.

Direct service worker wages & benefits

EDI direct service workers were paid a base salary of \$15 per hour in 2018. In addition to their base salary, direct service workers kept \$10 of the client's hourly co-payment and EDI received the \$5 balance, which made up three to five percent of the organization's annual budget.⁴ When the client fee was waived because of hardship, direct service personnel still received an additional \$10 per hour, the equivalent of the client hourly co-pay, for each hour they provide services. Thus workers could earn up to \$25 per hour for hours when they provided service for a client. Workers who work at least 24 hours per week for two consecutive months are eligible for health insurance that includes vision and dental coverage.

Impact

We interviewed EDI clients and staff who volunteered to talk with us so we could understand how they perceived the impact of services on client health and wellbeing and on the infrastructure they need to live successfully in the community.

that both client copays and employee share of copays will change in 2019.

⁴ Email exchange with EDI Executive Director Nikki Brown-Booker on September 5, 2019. EDI expects

EDI management and direct services staff consistently described the organization's primary role as supplementing critical support and care needs of disabled Berkeley residents. Most employees emphasized that the only alternative available to a disabled person when a PAS, equipment, or transportation emergency arose—after unsuccessfully seeking help from other PAS workers, family, or friends—would be to call 911. EDI therefore is filling a fundamental role in the community by bridging the gap between traditional scheduled services and unexpected emergencies.

Direct service staff report that the most satisfying aspect of their job is contributing to the client's quality of life, independence, and self-reliance by providing a service that is not available from other sources. One person said, "I would absolutely recommend this job to somebody." Another said, "I am totally passionate about...what we do, almost with missionary zeal in a sense. I'd love to...take this to other places."

Clients we interviewed reported functional mobility and vision limitations, and mental health issues. Some people said they had more than one disability. Most of them used one or more items of adaptive equipment including motorized and manual wheelchairs and scooters, Hoyer-type lifts, adjustable electric beds, ventilators, automatic door openers, shower chairs, and walkers. They reported needing EDI services as little as twice a year to as frequently as three or four times a month.

Client interviewees reported that they needed emergency equipment repair when a mobility or assistive device stopped working. Repairs are often needed, for example, when a wheelchair or scooter has a dead battery, a flat tire, or a broken recliner motor, joystick, or connector; or when the motor on an adjustable bed stops working.

Describing a recent EDI visit, one motorized wheelchair user said, "I was in a reclined, tilted position and my chair just completely stopped working. I was stuck and they came and fixed it." Another person said that the tiller on their scooter broke so they were unable to drive the device in reverse, which was necessary to use the elevator in their apartment building. The

repair technician met the person in the lobby of the building and repaired the scooter. The client said, "I have no idea how I could have gotten, you know, to the fifth floor of an apartment building because I couldn't go in reverse with the scooter. There's a huge level of anxiety relief knowing that I can call them."

Most interviewees commented on failed attempts to get services from a local equipment vendor with whom their health plan contracted for services. One person said, "They would come out in two or three weeks to take a look at what was going on. And then it would be at least another ten days to two weeks before they would order a part... There was no such thing as emergency service. So, they were useless."

Equipment repair technicians are in high demand and can receive five to eight calls during a daytime shift. They reported that flat tires and failed batteries were the most common wheelchair and scooter repair problems they encountered. EDI maintains hundreds of spare and loaner parts and equipment, so emergency repairs can generally be made on the spot.

In some cases, however, a wheelchair might need to be brought to the shop for more extensive repairs and a loaner would be provided, if necessary. The organization has available around 35 motorized wheelchairs for this purpose. EDI has built up a large inventory of loaner parts and equipment as a result of donations from community members when a family member dies or a person acquires new equipment. When they are not working with a client, technicians maintain the shop and the parts inventory and dismantle and repair donated equipment.

On-call transportation destinations typically included family visits and social occasions, medical appointments and dialysis, and trips to or from the hospital. Most wheelchair or scooter users who reported using EDI's on-call transportation service remarked that the service fills an important gap because taxis and ride-hailing services such as Uber and Lyft are not accessible and county paratransit services require a minimum of 24 hours' notice to reserve a ride.

Other clients noted that EDI emergency transportation had provided rides to their homes when their wheelchair or scooter broke down on the street. They said that if EDI services had not been available the only option would have been to call 911. In another example, police were called because a wheelchair user was having a psychiatric crisis at a public location. After paramedics transported the person to a psychiatric hospital, officers called EDI to transport the person's motorized wheelchair to the facility. Because first responders do not transport wheelchairs when they take someone to the emergency department or mental health treatment facility, disabled people frequently find themselves without their chairs, which can be stolen or lost when they are left behind in public places.

Workers and clients alike said that emergency personal assistance services can make the difference for some clients between remaining in their homes in the community and being forced into some type of institution. One client said, "If I was unable to receive the service, then that would require me to restructure and to move to a rehab. facility or old people's home. That...would be much more expensive and it would be emotionally and physically devastating." Another person, commenting on the value and impact of EDI's emergency PAS and equipment repair service said, "My personal freedom and independence is dependent on them. I'd live a hellish life, probably in a nursing home. And I'd be miserable."

New service demographic

Notably, many staff commented that the demographic the organization serves has changed significantly in recent years to include increasing numbers of homeless disabled people living in semi-permanent encampments or shelters in the Berkeley area.⁵ Many of these individuals have mental health or substance use disorders as well as significant functional

limitations and they face extreme hardships from living without stable, permanent housing. One of the most challenging aspects of the job for many of the direct service workers is confronting the fact that disabled people living in these locations experience layer upon layer of difficulty accomplishing simple tasks such as plugging in a motorized wheelchair, staying clean, and getting to the toilet.

The direct service technicians help with problems such as charging wheelchair batteries and providing assistive devices such as walkers and manual wheelchairs. They also described setting up solar panels within the encampments so people can have access to a way to regularly charge their motorized wheelchairs or scooters. While the staff does their best to serve this community, they face tough challenges every day. A response to a call from one person could lead to multiple requests for help from others once the technician is on site.

One worker said, "This morning I was at the men's shelter and I went in to fix one person's scooter and I did that, however, I also gave another person a battery charger...I tightened up somebody's front casters and there was a guy with this cable on his scooter that had snapped off, so I just screwed that back in." One person said, "I am there to help them live independently, however it's just screaming that they need help, they need advocacy, they need resources." At times the work is literally life-saving. One staff member reported rescuing a disabled homeless woman whose motorized wheelchair became stuck in the railroad tracks as she was traveling to her encampment only moments before an oncoming train would have hit her.

⁵ Frances Dinkelspiel, (2019). Berkeley now estimates 2K people experience homelessness in the city during the year. *Berkeleyside*, Berkeley, CA. Retrieved from

<https://www.berkeleyside.com/2019/04/05/berkeley-now-estimates-there-are-2k-homeless-people-who-come-through-the-city-in-a-year> on May 28, 2019.

Funding

Measure E

MEASURE E: Shall an ordinance be adopted imposing a special tax of up to \$0.008 (8/10 of 1 cent) per square foot of improvements, effective January 1, 1999 in the City of Berkeley to fund emergency services and incidental case management for severely physically disabled persons?^{6,7}

Measure E, approved by Berkeley voters in 1998, levies a small tax on Berkeley property owners, which pays for EDI's core services. Inspiration for Measure E and the success of the ballot initiative campaign were a product of the leadership of disabled Berkeley residents and the power of citizen advocacy. A small group of disabled advocates decided that, rather than competing for city funding each year, emergency services should get permanent funding through a modest tax. Group members worked closely with the City Manager to write the language for Measure E, collect the required number of signatures to place the measure on the ballot, and secure City Council support.⁸

The measure was unanimously endorsed in a 9–0 vote by the Berkeley City Council, because it ensured that Berkeley residents with significant

physical disabilities would receive appropriate, skilled assistance in times of emergency without relying on more expensive EMT, police, and fire services.⁹ Although there was little opposition to the proposed measure, the Chamber of Commerce expressed concerns about a tax increase, but their opposition ultimately did not affect the City Council's final decision. Following the Council's vote, activists moved quickly to raise money to publicize the ballot measure and launch the campaign, "Everyone agrees, vote yes on Measure E!" They also promoted the measure with numerous local groups and organizations and sought their endorsement, and conducted a door-to-door educational campaign.¹⁰

Explaining the need for Measure E, the sample ballot and voter information pamphlet for the November 3, 1998 general election stated that:

Severely physically disabled persons, as defined herein,¹¹ frequently require specialized emergency services, such as urgent response by an attendant, and transportation services and equipment repair. There is currently a serious shortage of both such services and in funding for such services. Lack of timely emergency services can threaten the life and safety of persons with severe

⁶ City of Berkeley Resolution No. 59,809-N.S. "Confirming the Canvass of Returns, Including Absent Voters' Ballots, of the General Municipal Election Held November 3, 1998, and Declaring the Results." Retrieved from City of Berkeley website, archived Berkeley City Council documents, January 2019.

⁷ The tax imposed by this ordinance is a special tax, which is authorized for elector approval by Section 4 of Article XIII A of the California Constitution.

⁸ Minutes, Berkeley City Council Regular Meeting, Tuesday, July 14, 1998. Retrieved from City of Berkeley website, archived Berkeley City Council documents, January 2019.

⁹ Oral history interview: Michael Pachovas, The Disability Rights and Independent Living Movement (DRILM), University of California Berkeley, Bancroft Library, July 18, 2001.

¹⁰ Oral history interview: Scott Luebking, The Disability Rights and Independent Living Movement (DRILM), University of California Berkeley, Bancroft Library, July 1998.

¹¹ "Severely physically disabled" shall mean subject to a physical impairment that substantially limits one or more of the major life activities of an individual such that the individual must rely on personal assistance services or equipment to perform a major life activity or to avoid being institutionalized. "Severely physically disabled" may include environmental illness/multiple chemical sensitivities if it substantially limits one or more of the major life activities of an individual such that the individual must rely on personal assistance services or equipment to perform a major life activity or to avoid being institutionalized. County of Alameda, Sample Ballot and Voter Information Pamphlet, General Election, Tuesday, November 3, 1998, Measure E, Section 4. Definitions.

physical disabilities...Measure E will enrich Berkeley by allowing severely disabled people to continue working and contributing to the life of our community.¹²

No argument against measure E was submitted.

Measure B

In 2000, voters in Alameda County, California approved Measure B, a half-cent transportation tax that enabled expansion of special transportation for seniors and people with disabilities, among other transportation improvements. This funding enabled EDI to add demand-response transportation for disabled Berkeley residents who establish paratransit eligibility.

Program strengths & challenges

Direct service worker experience & training

EDI clients and staff agree that worker experience, training, and familiarity with the independent living philosophy¹³ play important roles in ensuring and maintaining an effective emergency service. The overarching philosophy: “The client is the boss!”

Some direct service workers have been with the organization since its inception and some were even involved with EDI’s predecessor organizations. All PAS employees receive training on the types of assistance PAS clients might require such as safe lifting, transfer, and

dressing techniques; use of equipment such as Hoyer-type floor lifts; bowel and bladder care; wound care; basic wheelchair and scooter operation and maintenance; and operation of other equipment such as breathing devices. Moreover, years of experience has exposed long-term PAS workers to almost every type of functional problem that someone living with a disability might encounter, thus shaping and strengthening their skill sets and competencies.

While PAS worker turnover in the Medicaid PAS program in California is estimated to be about thirty-three percent annually,¹⁴ EDI reports that it has been able to retain a greater percentage of workers because of a unique blend of job flexibility and satisfaction, pay rates that exceed minimum wage when co-pays are factored in, and fit. For example, PAS workers are typically assigned shifts during which they are on call and must arrive at a client’s home within forty-five minutes after a dispatcher contacts them. Depending on service demand, however, the on-call arrangement occasionally permits workers the freedom to engage in activities of their choosing while they wait for a service call.

Other direct service workers who have been with the organization for many years have gained extensive on-the-job experience assisting disabled people resolve emergencies. Such breadth of experience ensures that these workers have the skills required to handle most complex problems, such as when crucial equipment like motorized wheelchairs malfunction. Typically, these longer-serving employees mentor newer

¹² County of Alameda, Sample Ballot and Voter Information Pamphlet, General Election, Tuesday, November 3, 1998, Measure E. The argument in favor of Measure E also stated, “If, unexpectedly, an attendant does not appear, a disabled person may have problems ranging from missing work or school, to health or life-threatening complications of the disability. At other times, unanticipated problems requiring immediate intervention may occur. Additionally, away from home, a disabled person is at risk when a wheelchair breaks or batteries die.”

¹³ “The Independent Living philosophy emphasizes consumer control, the idea that people with disabilities are the best experts on their own

needs, having crucial and valuable perspective to contribute and deserving of equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that powerfully affect their day-to-day lives and access to independence.” National Council on Independent Living (NCIL). <https://www.ncil.org/about/aboutil/> Accessed on June 27, 2019.

¹⁴ Sarah Thomason and Annette Bernhardt (2017). “California’s homecare crisis: Raising wages is key to the solution.” UC Berkeley Center for Labor Research and Education. <http://laborcenter.berkeley.edu/pdf/2017/Californias-Homecare-Crisis.pdf> Retrieved on March 19, 2019.

staff and share strategies for resolving the myriad of challenging emergencies they encounter every day.

Effects of changes in labor & housing markets

After twenty years of operation, EDI is experiencing the effects of broad, structural changes in the local labor and housing markets. While the organization has successfully retained some of its experienced PAS workers, disabled individuals and other service agencies find it difficult to attract people to the job. San Francisco Bay Area unemployment is at an all-time low and few people are interested in joining the PAS workforce because many other jobs they are qualified for pay higher salaries and offer better benefits and working hours.¹⁵ Moreover, housing costs have skyrocketed, pricing out low wage earners.¹⁶

This environment makes it especially difficult to recruit and successfully retain PAS workers. Disabled people who can afford to hire workers privately and pay a higher wage fare somewhat better, but still find it challenging to retain qualified workers. In both cases, PAS users are experiencing more gaps in services and therefore require more emergency assistance. EDI points to the PAS worker shortage as one of the most challenging problems that affects not only service demand and staffing, but also more importantly, the infrastructure that disabled people require to live independently with choice and dignity.

EDI reported that about twenty-five percent of people served in 2018 have mental health or substance use disorders as well as physical disabilities. Lack of affordable housing and other economic and social factors have forced many of these individuals to live in homeless encampments or shelters. Sometimes they contact EDI directly for help with broken assistive devices or for transportation. In other situations, Berkeley police, firefighters, or

EMTs rely on EDI to intervene when someone is intoxicated or abusive. They do so because they know that the experienced EDI staff likely can effectively support the person and potentially avoid an unnecessary trip to the emergency department.

While the majority of homeless people EDI serves have a physical disability that qualifies them for EDI services, some do not. For this reason, EDI has had to proactively find ways to serve this growing population while remaining in compliance with Measure E. For example, recent funding has enhanced their capacity to help people with mental health or substance use disorders and coordinate services with other local mental health organizations. Still, the structural problems that have contributed to homelessness call for systemic reforms and creative solutions that go beyond emergency services.

Service demands outside Berkeley

EDI is a unique organization that provides services that are not available in surrounding communities or indeed anywhere else in the country, as far as we know. Because Measure E restricts services to eligible Berkeley residents, with only a few exceptions, such as University of California Berkeley students, EDI staff report that there is extensive pent-up demand for them in the greater San Francisco Bay Area and beyond. The organization has worked to find ways to provide services to people who live outside the boundaries of Berkeley, but doing so means that alternative funding must be available or clients must pay privately.

Emergency PAS in Medicaid HCBS Programs

Federal disability rights laws and policies have spurred states to reduce Medicaid spending on nursing homes and other institutions and increase support for LTSS and HCBS, including

¹⁵ Sarah Thomason and Annette Bernhardt (2017).

¹⁶ Nour Malas. "California has the jobs but not enough housing." *The Wall Street Journal*. March 19,

2019. <https://www.wsj.com/articles/california-has-the-jobs-but-not-enough-homes-11553007600>. Retrieved on April 26, 2019.

PAS, so disabled people can remain in their homes in the community rather than be institutionalized. Because Medicaid is the largest single payer of personal assistance services in the United States, we include a brief overview of gap PAS that are spelled out in certain Medicaid contracts with states and Managed Care Organizations (MCO). While it is beyond the scope of this report to provide a comprehensive survey of emergency PAS and other services, we reviewed a sample of federal contracts that govern Medicaid managed Long Term Services and Supports (LTSS) programs for mention of backup or gap PAS services and implementation methods. Our goal was to facilitate a broad comparison of backup PAS provisions found in these contracts with the services EDI provides.

Of the 14 managed LTSS contracts we reviewed, 11 required that some type of backup plan for PAS be identified, but generally individuals who require such emergency services are expected to assume responsibility themselves for arranging backup care, in some cases with the assistance of a case manager or other social services professional. Two other contracts require that a contracted home healthcare agency provide backup services, but the details of how such contracts function practically appear to be left to the MCO's discretion. One contract requires live telephone contact for clients in case of a care emergency, but no information is provided that clarifies how the emergency will be handled.¹⁷

California's Medicaid managed LTSS program, which applies to seven counties, recognizes and delegates authority for operation of a PAS

worker registry to County entities called Public Authorities.¹⁸ The federal managed LTSS contract also calls for PAS emergency backup services. A review of a sample of county Public Authority policies, however, indicates that workers signed up with the registries are the only PAS needs backup available. This solution places responsibility on PAS users to request referrals from the registry—typically during business hours—then contact prospective workers and determine their availability and make arrangements for one or more shift substitutions.

Although this system could work when the person knows a worker will be absent for a particular shift in the future, it is impractical as a method to solve an immediate service emergency, such as when a worker calls in sick right before a shift or the person has a bathroom accident. Recognizing this limitation, several of the Public Authorities also recommend that PAS users be prepared for potential gaps in service by making arrangements with existing workers, family members or others before an emergency. One Public Authority even recommends billing regularly for a substitute worker, for less than an hour of work, as a method to ensure the worker's availability.^{19, 20, 21}

Our sample of Medicaid LTSS contracts revealed a broad general awareness of the need for emergency PAS, but implementation methods not only vary, but also rely significantly on advising clients to prepare for such emergencies themselves. In the absence of community-based programs like EDI, options for backup PAS either do not exist or are limited

¹⁷ University of California San Francisco, Community Living Policy Center, State Managed LTSS Programs. <https://clpc.ucsf.edu/state-info>. Retrieved on September 11, 2019.

¹⁸ University of California San Francisco, Community Living Policy Center, State Managed LTSS Programs. <https://clpc.ucsf.edu/state-info>. Retrieved on September 11, 2019.

¹⁹ Building Bridges to Independence and Dignity: A Consumer Guide to – Home Supportive Services in Alameda County. [https://ac-pa4ihss.org/wp-](https://ac-pa4ihss.org/wp-content/uploads/2017/02/Consumer-Guide-to-IHSS-4-16-2012.pdf)

[content/uploads/2017/02/Consumer-Guide-to-IHSS-4-16-2012.pdf](https://ac-pa4ihss.org/wp-content/uploads/2017/02/Consumer-Guide-to-IHSS-4-16-2012.pdf). Retrieved on September 3, 2019.

²⁰ Contra Costa County, California, Employment and Human Services, Area Agency on Aging. <https://ehsd.org/elderly-disabled/area-agency-on-aging/>. Retrieved on September 3, 2019.

²¹ Los Angeles County Department of Public Social Services, In Home Supportive Services (IHSS). <http://dpss.lacounty.gov/wps/portal/dpss/main/programs-and-services/in-home-supportive-services>. Retrieved on September 3, 2019.

to Medicaid worker registries or costly home healthcare agencies.

Conclusions

EDI's effectiveness and client satisfaction, along with its service philosophy, funding structure, and longevity make it a unique and promising practice that provides emergency PAS, transportation, and assistive equipment repair services for disabled people. Certain other aspects of its history and record also add to its significance. EDI was founded and has consistently been directed by disabled people who themselves have experienced the life-altering impact of gaps in PAS, emergency repair of wheelchairs and other devices, and limited or no accessible on-demand transportation. Built on their vision and experience and rooted in independent living principles of autonomy and self-determination, this model fills these critical service gaps and helps disabled people with significant functional limitations live independently and safely and participate fully in their communities.

Unusually, it also operates with stable annual funding for its core programs from a small Berkeley tax and from other funding measures. Such funding stability has ensured the organization's continued operation, irrespective of management and other operational challenges over time. Moreover, EDI's experience also suggests that locales can save money on police, firefighter and EMT costs and also reduce health care costs related to emergency department use when less expensive emergency services are available.

While EDI has operated for over two decades, we are not aware of other communities that have tried to adopt a similar model. Even as the organization's experience shows that gap services can replace the need for first responders and emergency departments, locales have not shown much interest in establishing similar programs.

Although the reasons are not fully understood, it is likely that local government leaders think that gap emergency services fall within the purview of social services, traditional welfare agencies,

or perhaps healthcare, and therefore are a federal or state responsibility. Moreover, local governments are not likely to look favorably on raising property taxes for this purpose, even as first responders and emergency departments might bear the brunt of managing problems arising from lack of dedicated emergency services for disabled people.

Whatever the reasons, disabled advocates and municipal leaders alike should explore the EDI service model, along with various funding mechanisms and collaborations with local, state and federal stakeholders. Specifically, they should investigate partnering with Medicaid MCOs that are already in the business of providing or overseeing personal assistance services for specific groups of disabled and older people. Such partnerships could create a path for their community to meet services gaps as the population ages and more and more people with significant functional disabilities live and work in communities of their choice, rather than being needlessly institutionalized.

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