Announcements from ACL

Caroline Ryan, Manager of VA and CMS Partnerships and Innovation
Office of Interagency Innovation
Agenda

- Welcome and Announcements from the Administration for Community Living (ACL)
- Veterans Health Administration (VHA) Announcements
- VDC Evaluation Part 3: Veterans’ and Caregivers’ Experiences in VDC
- Applied Self-Direction: *Paying Family Caregivers to Provide Care during the Pandemic*
- Closing
VDC Evaluation: Overview of Webinar Series

• VDC evaluation funded by VA and conducted by:
  ► VA’s Partnered Evidence-Based Policy Resource Center (PEPReC),
  ► Center of Innovation in Long-Term Services and Supports (LTSS-COIN), and
  ► The Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT).

• Findings from the evaluation presented over multiple webinars
  ► **Building VDC Partnerships** (occurred on July 15)
  ► **Impact of VDC on Veterans’ Health and Healthcare Utilization** (occurred on September 30)
  ► Experiences of Veterans and Caregivers
Announcements from VHA Regarding VDC

Daniel Schoeps,
Director, VA Purchased Long-Term Services and Supports
Veterans and Caregivers’ Experiences Accessing the Services & Supports of Veteran Directed Care

Kali S. Thomas, PhD and Ellen K. Mahoney, PhD, RN
February 24, 2021
What We Already Know

- Veteran-centered care and increasing alternatives to nursing home placement are top priorities for VA leadership.
- Research suggests Veteran Directed Care (VDC) has been successful in limiting hospitalizations and nursing home placement, and Veterans and caregivers like this program.
- However, uptake of VDC has been limited and challenges exist in program implementation.
What This Study Sought to Understand

- How Veterans and their caregivers access and use the program
  - Important to program development/improvement
  - Generate recommendations to improve access
Research Methods

- Mailed letters and followed up by phone to Veterans at 11 VAMCs
- Enrolled 24 participants (16 Veterans, 8 caregivers)
- Semi-structured interview
  - Asked about experience enrolling and participating in VDC; how VDC impacted participant’s daily life; how the program could be improved
- Interviews recorded, transcribed, and coded using conventional content analysis
- Interviews took place from May 2018 to February 2019
Main Findings - Overarching Themes

- Theme 1. Veterans’ experiences accessing VDC varied.
- Theme 2. Once in the program, Veterans were able to purchase goods and services that were meaningful, important, aligned with Veteran-centered care, and met their needs, many of which were unmet before; but, some components of the program limited the services they could receive.
- Theme 3. Veterans and their caregivers experience dignity in the program and want other Veterans to have access to VDC.
Theme 1. Veterans’ Experiences Accessing VDC Varied

1a. Providers at the VA recognized Veterans’ needs and helped them enroll

- “She was my social worker in the hospital...Once they got to know me in the hospital a lot, she asked me would I need this program, so I said, yes... I would not have been noticed for this program if I had not been hospitalized a lot.” (Veteran)
- “I was in a nursing home and it ended up I had to be admitted to the hospital, and so they asked if I wanted to go back and I said, no... I wanted to go home ... they said this would be the safest way to go home.” (Veteran)
Theme 1. Veterans’ Experiences Accessing VDC Varied

1b. Veterans and their caregivers were self-advocates

- “I finally raised the white flag.” (Veteran)
- “Me contacting the chief of staff, the deputy chief of staff, the chief of geriatrics our congressman, and a few other people within the system, after, I want to say 15 months, we were finally able to get it.” (Caregiver)
Theme 1. Veterans’ Experiences Accessing VDC Varied

1c. It just happened

- “I’m glad that his name finally came up or whatever it was.” (Caregiver)
- “I didn’t volunteer for the program, the program selected me some way... I don’t know. Perhaps you did it alphabetically, and B comes to the early part of the alphabet.” (Veteran)
Theme 2. Access to Services in VDC

2a. Veterans able to obtain services that matched their needs

- “The girl in the daytime does the personal grooming, that’s bathing and grooming, getting me dressed, and getting me up and on my way. If I need to go anywhere she’ll drive me and take me there. And my needs in the afternoon, that specific caregiver does the bowel and bladder, she also puts me back in bed, prepares my food, and she turns me at night, 7, 9, 11, 1, and 3:00.” (Veteran)
- “Oh, the air conditioner broke, and it helped fix the problem. Bought new handles to get in and out of the shower. Paid for snow removal. Bought a back brace when walking outside. I have COPD, and it's helped me buy good furnace filters. Before, I’d just get the cheap ones. At least now I can kind of afford to get some for my allergies. I've got COPD. I have sleep apnea. Just giving me better, cleaner air. The electric used to go out a lot in our home, and we bought a whole-house generator because I need it for my sleep apnea machine and my nebulizer, and that seemed to be a real lifesaver as far as staying in my home. It's helped make the basement steps safer. They were a little rough, and we put some nonskid pads down on them. I know it sounds like we bought a lot of stuff, but we have....And so that's made a big difference in my life.” (Veteran)
Theme 2. Access to Services in VDC

2b - Access to options counselor

● “She gives me a lot of suggestions.” (Veteran)
● “Everything from the help with Meals on Wheels to everything in the beginning they set up – they helped me with my prescriptions, they helped me with, everything. They took care of making sure that I was taken care of and that I needed everything and now they’re still doing it... She’s there if I need anything. She knows now that my cancer has come back and she’s really on top of it to see if it’s getting better or worse. You know, she’s asks about my family, about my dogs. For her to call me once a month is just fantastic... anything that I needs, these people are behind me.” (Veteran)
Theme 2. Access to Services in VDC

2c. Some program rules limit Veterans’ access to goods and services

- “I wanted my sister-in-law to come to work for me. ... I've known her since she was 13... She wound up in trouble and had to go to jail for 30 days, and that was a felony. Well, I wanted to hire [name] as my permanent caretaker, and I wasn’t allowed to, because she had a felony... And then someone else couldn’t get hired because they had a DWI from years and years before. And this was a woman that had already been working for me in that other program the VA had.” (Veteran)
- “The current drawback is that flex spending if outside primary care is difficult to manage. i.e. hair care. They have to do a 1099. Drawback because most do not want to do the paperwork.” (Caregiver)
Theme 3. Veterans and Caregivers Experience Dignity and Want other Veterans to Have Access to VDC

3a - Veterans and caregivers experience dignity

- “Now all of a sudden he’s got some responsibility, he gets to hire somebody, he gets to pay somebody, he gets to thank somebody, and say, “you’ve done a wonderful job,” and smile again, because the person that’s coming to the door is a good family member or a good worker... So that’s being a man again... I love that thought of giving the Veterans a chance to be a man.” (Veteran)
- “I mean my wife helped too, but I honestly believe she should get something for that because even though my wife loves me, I know it's hard on her, and I don’t want her to lose interest in me just because I’m getting old and think I'll just put him in a home somewhere. And by her receiving some money for her time, it kind of makes her feel like she's important also.” (Veteran)
Theme 3. Veterans and Caregivers Experience Dignity and Want other Veterans to Have Access to VDC

3b - Veterans and caregivers want other Veterans to have access to the program:

- “I go to the VA a lot to my appointments, and I'll be sitting there waiting. I'll talk to different veterans. We just talk a lot, and I'll recommend them to the program that I’m on. I'll tell them to call their social worker and ask them about the program. I know it helped me, so I know it would help another Veteran.” (Veteran)
- “Any Veteran that I know of, I tell about it” (Veteran)
- “He has early dementia, so that's never going to get any better, but the program itself is a great program if they would just give it to the medical centers.” (Caregiver)
Recommendations

- Expand the program to more Veterans
- Ensure Veteran-facing healthcare professionals know about VDC and how to access it
- Think about outreach to Veterans at risk - before they need to "raise the white flag"
- Provide flexibility in using budget for goods and services, including having discretion in how to use savings fund and caregiver selection
- And, enroll more Veterans
Acknowledgements

- Funding from VA HSR&D (CDA 14-422, PI: Thomas; SDR 16-194, PIs: Rudolph, Sperber, Thomas)
- Assistance from Taylor Rickard and Dawn Mello
- Veterans and caregivers participating in this research
- All of YOU for your service to Veterans through VDC!

  - “I think those folks ought to get letters of recommendation, or appreciation just to say thanks... they always tell me over the phone, “thank you for your service.” Well, I know I served, and I did a lot for my country, but what this program has done and what the VA itself has done almost exceeds what I did.”
  (Veteran)
Questions?

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Paying Family Caregivers in Self-Direction
Introduction

Self-Direction
- An established and successful model available in every state serving a variety of populations

COVID-19
- Presented significant challenges to providing personal care, but also highlighted the value of self-directed programs

Family Caregivers
- Many states have newly allowed paid family caregiving in Medicaid programs in response to COVID-19
Self-Direction Trends
Self-Direction Continues to Grow

Self-Direction National Enrollment Over Time

<table>
<thead>
<tr>
<th>Year</th>
<th>Participant Enrollment</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>800,000</td>
</tr>
<tr>
<td>2013</td>
<td>800,000</td>
</tr>
<tr>
<td>2016</td>
<td>1,200,000</td>
</tr>
<tr>
<td>2019</td>
<td>1,200,000</td>
</tr>
</tbody>
</table>
Mostly Medicaid

Number of Self-Direction Programs by Funding Source

- Medicaid: 66%
- VHA: 23%
- State Funds Only: 4%
- Other: 7%

Legend:
- Medicaid
- VHA
- State Funds Only
- Other
## VDC Trends: 2016 - 2019

<table>
<thead>
<tr>
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<th></th>
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</thead>
<tbody>
<tr>
<td>State Count</td>
<td>31</td>
<td>41</td>
<td>32% increase</td>
</tr>
<tr>
<td>Veteran Participants</td>
<td>1,572</td>
<td>2,048</td>
<td>30% increase</td>
</tr>
<tr>
<td>Program Count</td>
<td>60</td>
<td>71</td>
<td>18% increase</td>
</tr>
<tr>
<td>Multiple Programs</td>
<td>12</td>
<td>15</td>
<td>25% increase</td>
</tr>
</tbody>
</table>
Self-Direction Enrollment and Program Size

- Total enrollment is over 1,200,000
- Number of programs is approximately 260
- Average program size is about 4,500 participants
  - Range is from 1 to 300,000

Data source: 2019 National Inventory
Majority of States have 1,000 – 5,000 Participants Self-Directing

Data source: 2019 National Inventory
Impact of COVID-19
Workforce Shortage

- There is an ongoing nationwide shortage of direct care workers and high turnover within the industry
  - Low wages
    - Median hourly wage for home care worker: $12.71
    - Median hourly wage nationwide: $19.33
    - Wages are set by Medicaid and not subject to market forces
  - High levels of physical and emotional strain
COVID-Specific Workforce Shortages

- Closures of school and daycare have made it more difficult for home care workers to leave their families.
- Concerns of risk for contracting COVID by workers employed by multiple households.
- Unemployment compensation is competitive with Medicaid rates, making it easier and safer for workers to stay home.
COVID-19 and Nursing Homes

- Exacerbated Social Isolation
  - Reduction in both physical and mental health

38% of Deaths

5% of total COVID-19 cases
Multiple factors combined in nursing homes to create an environment in which COVID was difficult to contain, including:

- Inadequate infection control and prevention practices
- Shortages in personal protective equipment
- Insufficient staffing
- High levels of interpersonal contact
Turning to Family Caregivers

- Safety
  - Many family caregivers already live with the care recipient, reducing exposure risk
  - Family members not living with the care recipient offer lower risk than homecare workers traveling between multiple homes
- Reduced isolation for individual
- Consistency and continuity of care
  - Lower turnover rates
- Compassionate and trusted support
  - Tasks performed by caregivers typically require close contact and sensitivity
Restrictions Prior to COVID-19

- Many states had longstanding restrictions on the types of family members who Medicaid beneficiaries could hire as caregivers
- 144 programs of 262 nationally did **not** allow at least some types of family caregivers to be paid for their work
Barriers to Paying Family Caregivers

Assumption
- Spouses should not receive payment because it is expected in the spousal relationship

Reality
- Caregiving needs are often strenuous and beyond traditional levels of supporting a spouse
- Spouses are often responsible for both caregiving and providing financially
- Spousal caregivers often must choose either to:
  - Work and outsource caregiving to a home care worker
  - Not work and stay home to provide care
- Spouses working outside the home increases risk of COVID-19
Family Caregiving Does Not Increase Fraud

Assumption
- Family caregiving and self-direction are highly susceptible to fraud

Reality
- Research shows that fraud is extremely rare in Medicaid-funded self-direction and does not occur at a higher rate than in other Medicaid personal care services
Over 15 states issued temporary emergency rule changes permitting participants in self-direction programs the choice to hire family members.

These changes varied widely in scope, since states did not have uniform policies on which family members were permitted to provide care before the pandemic.

c_x_ Temporarily permit payment for services rendered by family caregivers or legally responsible individuals if not already permitted under the waiver. Indicate the services to which this will apply and the safeguards to ensure that individuals receive necessary services as authorized in the plan of care, and the procedures that are used to ensure that payments are made for services rendered.

Personal Support Services, Personal Support Extended Services, Consumer Directed Personal Support Services, and Out of Home Respite will be allowed to be provided by family caregivers or legally responsible individuals. Family Caregivers or legally responsible individuals will need to be employed by traditional providers or enrolled through the fiscal intermediary as described in the approved waivers. The standard enrollment process for provider agencies will provide safeguards for background check, training, and health and safety of members. Service utilization will continue to be authorized via prior authorization and existing audits and edits in MMIS. Auditing functions from MMIS, DCH Policy staff, and OIG will ensure that payments are made for services rendered.
Paid Family Caregiving
States Allowing Paid Family Caregivers for Adults 65+ and Adults with Physical Disabilities, Nov. 2020

- Allows Paid Family Caregivers:
  - No
  - Yes, all family members allowed in policy predating COVID-19
  - Yes, policy changed temporarily in response to COVID-19
  - Yes, some family members allowed in policy predating COVID-19

Map showing the states with different levels of allowing paid family caregivers.
Benefits of Paid Family Caregiving

- Paying family members expands the pool of available caregivers
  - COVID-19-related budget shortfalls will make it unlikely that states will be able to raise Medicaid reimbursement rates
  - It is unlikely that workforce shortages will cease
- Receiving monetary compensation for services provided makes family caregiving sustainable
  - The demands of family caregiving are often so great they preclude the caregivers’ ability to maintain other employment
- Increased availability of the limited professional direct care workforce for those not wanting or able to hire family
Benefits of Paid Family Caregiving

- The vast majority of adults ages 50 and older prefer living at home to in a nursing home
- Nursing home care is far costlier on average self-directed care
Conclusion

- Veteran-Directed Care is an integral part of a well-established and growing movement to enable people to manage their own care at home.
- In the wake of the pandemic, the public’s understanding for the need for self-direction has increased.
- Many practices already in place in VDC programs are becoming more common in Medicaid and State-Funded programs as well.
- These changes, if made permanent, could help solve multiple ongoing concerns in Medicaid, including workforce shortage and issues of safety.
Questions?
VDC Provider Highlight: Area II Agency on Aging

Billings Gazette Article Feature: As VA Paid Caregivers, Family and Friends Anchor Montana Vets to their Homes
Closing

• VDC Monthly Reporting Tool Data Entry:
  https://app.smartsheet.com/b/form/9bff196f995e4ddd82aa0fd246ae0501

• VDC Survey Questions:
  https://app.smartsheet.com/b/form/4d40b6d0a5ca44ad994a68c7aed5cdb3

• VDC Provider Suggestion Box:
  https://app.smartsheet.com/sheets/jxPv6q8cMH5H5GcFMXMrFM7X4jrWxFhFXCV6cfm1?view=grid

• Please email the VDC Technical Assistance Team with any questions: veteranandirected@acl.hhs.gov