

Communities rely on nonprofits; nonprofits rely on accurate census

By David L. Thompson

A full and accurate count of all residents in the United States is vital to your democracy, to the well-being of our communities and, indeed, to the successful operations and missions of charitable nonprofits. This is an article intended to give proof to that last assertion – that the Census is essential to charitable organizations – but first the news, both good and bad.

The good news is that Congress came through with significant funding so the Census Bureau can proceed with the planning for the constitutionally mandated decennial count of every man, woman and child in the country. After years of short-changing the Census Bureau, Congress appropriated \$1.3 billion for the remainder of the current fiscal year. Some complain, justifiably, that the amount is too little too late. But the Census Bureau is shifting into high gear and is aggressively reaching out to charitable organizations to enlist our help in securing a complete count.

The bad news suggests that no degree of planning and spending will correct for changes that are guaranteed to create an incomplete and inaccurate count. On March 26, the Commerce Secretary announced that the Census 2020 questionnaire will ask all participants whether they are U.S. citizens. State Attorneys General, mayors, nonprofits and others working to promote a full and accurate census are concerned that the citizenship question will likely create fear among certain populations who believe the government will use the responses (or non-responses to certain questions) as an excuse to take actions against individuals. The acting Census Bureau chief acknowledged as much in a public hearing last month when he rejected the suggestion that the question would have little effect, stating: “I wouldn’t say minimal. It could be, in some communities, important.” The fear is that the citizenship question could depress the number of responses from immigrants and residents, producing an undercount disproportionately affecting those populations.

Imagine if new immigrants to Massachusetts from war-torn countries were asked by federal government officials whether they are citizens. It is understandable, and to be expected, that people who have fled government oppression or who do not have proper documentation, would avoid the risk of being counted, and punished. And that is the most important point for charitable nonprofits.

Many people have focused on what an inaccurate census count can mean to the allocation of congressional and legislative district seats and of rural versus urban representation. But for nonprofits, as well as city and state governments, the

more direct consequence of a bad census count comes from the misallocation of resources as undercounted communities will then be further underfunded. Census data are used in about 300 federal programs to determine where more than \$800 billion in federal funds are allocated every year. If the data are wrong, there will be inequitable distribution of resources for basic community needs, meaning Massachusetts won’t get its fair share of resources.

The Role for Providers

Certain hard-to-count populations and communities historically have been prone to undercounting, inaccuracies and under-reporting in census data. People of color, high density urban areas, rural areas, LGBTQ, young children and non-native English speakers are disproportionately harmed by undercounting. These vulnerable populations are the ones who most often look to nonprofits for help with things like food, shelter, after-school programs for at-risk youth, and community-based solutions. When hard-to-count populations become even more difficult to count, nonprofits cannot properly plan or consider their services.

In short, all charitable nonprofits have a significant state and role to play in ensuring that all residents are counted as part of the 2020 Census. All of us have the opportunity to engage and help ensure a fair and accurate count, particularly in hard-to-count areas. Several ways to engage on the issue include:

- Convene and educate community leaders and other stakeholders, including the media, about the Census.
- Identify and partner with organizations and community stakeholders that are already connected to hard-to-count communities and have built strong relationships and trust.
- Advocate to federal, state and local lawmakers for funding to support census outreach efforts.
- Work with commonwealth, county, tribal and local government leaders to create and engage in Complete Count Committees (volunteer committees of government and community leaders from different sectors established to increase awareness about the census and promote participation).
- Connect to national hubs (e.g., Census Project) that are providing resources to learn more about and engage in census advocacy.
- Use the Census Project (www.thecensusproject.org) toolkits to take action.
- Go to the National Council of Nonprofits website for more information. www.councilofnonprofits.org/trends-policy-issues/us-census-2020

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Change is never easy: MassHealth moves to accountable care orgs

By Bill Henning and Dennis Heaphy

On March 1, Massachusetts followed the lead of other states by enrolling people on MassHealth into new Accountable Care Organizations (ACOs). The change impacts up to 1.2 million MassHealth members, with at least 80,000 being people with behavioral health, intellectual, sensory and physical disabilities as well as complex care needs and chronic conditions.

For these consumers with thin margins of health and complex needs, who have knitted together very fragile networks of care, disruptions in their networks resulting from misalignment of providers or hospitals could be a big problem.

Tom Wilga of Bedford, who has quadriplegia, said the ACO process has been “somewhat arduous.” He connected with MassHealth staff after a referral by a disability advocate and switched ACOs to retain specialists. He was receiving care from two hospitals, a community health center and a rehab hospital. But he remains unclear on who’ll be maintaining his Baclofen Pump, vital to controlling spasms, which is critical to him functioning normally. He may have a new supplier for medical supplies and says, “I’m in No Man’s Land, I can’t pay for this, I’m a working Joe.”

Another issue consumers, advocates and providers alike are paying attention to is the so-called 90-day lock-in. This is a requirement that will prevent people from changing from one plan to another after three months, though there are exceptions. If a plan is not working for someone, the person should get a change in motion as soon as possible.

In a meeting in February, EOHHS Secretary Marylou Sudders said, “Our top priority are our members,” while MassHealth Director Dan Tsai said, “We really want seamless transitions for our members.”

Many advocates have stressed that when presented with issues, MassHealth staff have been quick to respond. Nancy Houghton of Beverly fits this profile. She was switched to an ACO that did not accept the range of specialists she had connected to at a Boston hospital, enabling her to live independently with rheumatoid arthritis, osteoarthritis and pulmonary fibrosis, among other conditions. She spoke out at a disability forum, received hands-on support from MassHealth, and now is in a stable situation. But she emphasizes that “People can’t lay down and take it: You have to ask questions, see if there’s another option for you – it was life or death for me, literally!”

Suzanne Curry of Health Care for All encourages “human services and social services provider organizations to reach out to newly formed ACOs to explore how to best collaborate to address the needs of their clients.”

The new system may be confusing for providers and consumers alike. There are 17 ACOs and some offer access to the full array of MassHealth providers, while others have narrower networks. Primary care providers are permitted to contract with a single plan. Some specialists, acting as primary care providers, may not be recognized as a primary care provider by a plan.

One effort that’s part of the ACO initiative is the creation of Community Partners (CPs), 26 groupings of human service agencies that are contracting with ACOs to support persons with significant behavioral health needs and those with disabilities with concerns around long-term services and supports (LTSS).

Jeff Keilson, Senior Vice President of Strategic Planning with Advocates in Framingham, said “The service provider community is collaborating on the significant work ahead to ensure that Community Partners reaches its full potential ... We are energized by the launch of this initiative.”

CPs will start serving consumers on July 1. Perhaps the biggest worry that’s emerged is that huge caseloads may not allow care coordinators at CPs to work extensively with consumers on matters such as social determinants of health – including the profound need for affordable housing – which often take extensive individual hands-on work to resolve.

One concern we have comes from the experience with One Care, the plan for those on both MassHealth and Medicare. When it started in 2013, many people with the most complex needs, those who are homeless, have a mental health diagnosis or a combination of needs, were not able to be reached in the first 90 days of enrollment. It will be important that those in similar situations with ACOs in 2018 have flexibility to switch plans if necessary to ensure quality services and care.

While there are real concerns about people keeping their medical team, along with new rules, terms and names to learn, we do wish to emphasize why ACOs can be a plus. Not everyone has been able to create coordinated networks of care, and a key part of ACOs are coordinated care teams that are supposed to emphasize community-based services. If clicking, this can really help people to live healthier, independent lives.

Those with individual concerns can contact the MassHealth Customer Service Center at 800-841-2900. If you have identified a larger, systemic issue, please feel free to contact Disability Advocates Advancing our Healthcare Rights (DAAHR), bhenning@bostoncil.org or dheaphy@dpcma.org.

Bill Henning and Dennis Heaphy are DAAHR co-chairs. Henning is director of the Boston Center for Independent Living and Heaphy is a health policy expert with the Disability Policy Consortium.

Faces in the crowd at the Seventh Annual Caring Force Rally



The Seventh Annual Caring Force Rally brought people from across the Commonwealth to the State House on April 10th to advocate for human services. At left, the crowd applauds rally speakers. Above, a group from Seven Hills Foundation takes a picture with Matthew Ritter, left, Chief of Staff to Sen. Michael Moore after discussing the student loan repayment bill.



Above, rally speakers Taylor Powers, left, of Bay Cove Human Services, and Jasmine Davis of Roxbury Youth-Works stop for a picture.