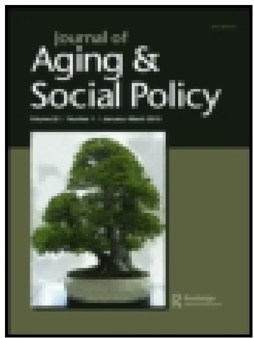

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Special Need Pooled Trust Disbursements and the Well-being of Nursing Facility Residents Receiving Medicaid Benefits

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ABSTRACT

Medicaid is the largest health insurer in America, comprising one-sixth of the nation's total healthcare expenditures. Of this, 40% covers long-term care services for older adults and adults with disabilities. Yet, Medicaid does not provide access to all goods and services needed. Pooled special needs trusts (pooled trusts) are a program through which older individuals, requiring long-term care, may set aside assets and remain Medicaid eligible. Pooled trust funds purchase items such as medical devices, telecommunications and funeral services. This article explores the relationship between Medicaid, pooled trusts and their role in nursing home residents' well-being. To understand this relationship, a descriptive study sorts the disbursements from a pooled trust into the 5 Gallup-Healthways Index well-being domains. The analysis shows that pooled trust funds purchased goods and services related to well-being. Thus, pooled trusts offer a means for states to expand the support they provide individuals in nursing facilities beyond the medical services covered by Medicaid to include goods and services associated with well-being.

KEYWORDS
Medicaid; pooled trusts; well-being; older adults; nursing facilities

Introduction

According to the Centers for Disease Control and Prevention (L. D. Harris-Kojetin et al., 2019), as of 2016 there were 1,347,600 residents in 15,600 nursing facilities across America. Of these facilities, 95% are Medicaid certified with 61.8% of the residents reliant upon Medicaid as the payer (L. D. Harris-Kojetin et al., 2019). States and the District of Columbia (together will be referred to as states for the entirety of this paper) spend on average 16% of their budget on Medicaid and when the matching federal funds are added to states' budgets, this spend rises to 28.9% of state budgets

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(Medicaid and CHIP Payment and Access Commission (MACPAC),). While Medicaid provides essential goods and services, it does not cover all personal needs.

The federal government requires that state programs cover services such as inpatient and outpatient hospital services, nursing facility services, physician services, laboratory and X-rays, and transportation to medical care. Other services are optional, such as prescription drugs, physical and occupational therapy, speech and hearing services, respiratory care, some diagnostic, screening and rehabilitative services, podiatry, optometry, dental coverage, dentures, prosthetics, hospice care and eye glasses, just to name a few. Most states do offer some of these services as part of their program, but virtually no state covers all related expenses. All non-covered "personal needs" are to be paid for by a small personal needs allowance (PNA), which is deducted from the general requirement that all of the Medicaid recipient's income must be paid to the facility while receiving benefits. The federal minimum PNA is 30 USD a month, set in 1987. The National Long-Term Care Ombudsman Resource Center reported that as of 2009 the mean PNA provided by state Medicaid programs was 49.69 USD (Ortiz, 2009). Therefore, many individuals dependent upon Medicaid may not have access to all the goods and services needed to maintain a healthy and reasonable life while residing in a nursing facility.

Defining pooled trusts

The federal Medicaid statute allows special needs trusts to be excused from the financial eligibility limits of Medicaid, so that these funds may be used to support the individual while public benefits continue to pay for basic medical care. The goal for allowing pooled trusts is to address gaps between the goods and services provided by state Medicaid programs and those required to sustain independence, comfort and dignity while residing in a nursing facility. All states allow pooled trusts however, some impose a penalty for transferring assets into a pooled trust after the age of 64 (Winston, 2019). In a brief presented at the 2019 pre-conference meeting of the *Special Needs Trusts: The National Conference*, according to a report from Attorney Laurie Hanson, " . . . seventeen states and Washington DC (AL, AK, CA, DC, DE, FL, IA, IN, ID, KY, MA, MD, MT, OH, RI, TN, WI, and WV) do not have penalties for fund transfers. Twenty-three states (AR, AZ, GA, HI, LA, ME, MS, NC, ND, NH, NJ, NM, NV, OR, PA, SC, SD, TX, UT, VA, VT, WA, and WY) do have penalties for transfers. Eleven other states (CO, CT, IL, KS, MN, MI, MO, NE, NY, and OR) may or may not have penalties for transfers depending on certain factors or the state policy is unknown" (Winston, 2019).

The federal requirements for all special needs trusts include (1) that the trust benefits only one person with disabilities, and (2) that it reimburses the

Medicaid program from amounts left at death for medical benefits paid during lifetime. Additionally, the federal government requires that funds from the trust may be used for purchases during the individual's lifetime and cannot be disbursed after the death of the individual except for payment of the Medicaid lien.

Pooled special needs trusts are subject to an additional requirement that they be administered by a nonprofit organization through a pooled asset program, which holds separate accounts for multiple individuals with disabilities. "Pooling" refers to the fact that the same rules for investing and distributing funds applies to all accounts. In a pooled trust each person is only entitled to funds from his or her separate assets that were deposited into the program (*See* 42 U.S.C. §1396p(d)(4)(C)). Persons aged 65 or older are given *only* the option of a pooled trust when seeking Medicaid eligibility. In contrast, assets in a special needs trust administered by a private trustee or individual, rather than by a nonprofit pooled trust organization, are not exempt from Medicaid eligibility rules for persons over age 64, even if the trust reimburses the state and otherwise meets the criteria for exemption.

The parameters guiding how funds in a pooled trust account are applied is determined by the nonprofit trustee organization. Such pooled trusts typically pay for goods and services as basic as clothing, a telephone or a haircut, or as critical as a replacement hearing aid, social support or transportation to social and community events. When considering placing assets into a pooled trust, individuals should closely review the organization's disbursement policy as well as state regulations which may include penalties for participation in the pooled trust.

Defining well-being

According to the Centers for Disease Control and Prevention (2019), well-being is a broad concept that includes feelings that range from joy to depression. Generally, research agrees that well-being includes positive emotions (e.g., happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfillment and positive functioning (Diener & Chan, 2011). In essence, well-being is a feeling or a state of being. What creates this state of being is the source of many studies. Several studies have investigated the correlates of well-being and found that one of the strongest predictors is healthy relationships (Reis et al., 2018). Other correlates include access to resources, having basic needs met such as housing, food, and clothing, and access to modern conveniences such as electricity (L. D. Harris-Kojetin et al., 2019; Frey & Stutzer, 2002). Additionally, a number of studies have shown a positive relationship between well-being and health status and longevity (Diener & Chan, 2011).

As part of these efforts to determine what causes well-being, a variety of measures have been developed. And much like our understanding of well-being, they have evolved over time. Currently, an array of tools is available that measures well-being. Some measure the singular construct of happiness and others which are more nuanced, measure different facets of well-being. One tool has broad acceptance, use, and support by decades of research: the Gallup-Healthways Well-Being Index. The Index is a population-based measure which is the result of intensive review of extant well-being research as well as extensive pilot testing in the United States and internationally. Gallup's analysis revealed five distinct domains: physical, purpose, financial, social, and community well-being. These domains are defined in their 2017, *State of American Well-being* as:

- Physical well-being: "having a sense of good health and enough energy to get things done on a daily basis."
- Purpose well-being: "liking what you do each day and being motivated to achieve your goals."
- Financial well-being: "managing your economic life to reduce stress and increase security."
- Social well-being: "feeling like you have supportive relationships and love in your life."
- Community well-being: "liking where you live, feeling safe, and having pride in your community."

This five-domain model of well-being is unique in its broad applicability, having supported research in over 150 countries, across many different languages, cultures, and life situations (Gallup, 2014). Because of this broad acceptance and its multifaceted construct, it is this model of well-being that will be used to investigate how pooled trust funds are used in relationship to well-being.

An analysis of pooled trust disbursements

While Medicaid programs afford beneficiaries access to goods and services related to treatment in a nursing facility, they do not and cannot meet all the needs of individuals reliant upon those programs. The PNA helps bridge this gap, by providing individuals with the means to address some well-being needs, yet the PNA has not kept up with inflation. Pooled trusts offer a means to supplement the PNA and afford individuals access to the goods and services that may not otherwise be affordable.

In order to understand how pooled trust funds are used and their relationship to well-being, aggregated, de-identified, secondary data of pooled trust disbursements from Guardian Community Trust were analyzed. Guardian

Community Trust is a Massachusetts-based nonprofit that manages a pooled trust program for older individuals. The study goals were to answer the following two questions:

(1) How are pooled trust funds used?
(2) What aspects of well-being are supported by the pooled trust disbursements?

Methods

Secondary data from Guardian Community Trust, comprising 864 cases, whose accounts opened between May 2005 and June 2018 and closed between January 2015 and December 2018, were used. The average size of an individual trust account's total deposits was 89,283.70. USD One hundred and forty-eight cases (17%) had a total deposit value of over 150,000 USD and 419 cases (48%) had a total deposit value of 50,000 USD or less. The modal deposit value was 25,000. USD Data elements analyzed for this study included the total deposits and the amount and nature of each disbursement. The nature of each disbursement was defined by the accounting staff of Guardian Community Trust independently of this analysis. Excluded from the analysis were expenditures related to closing the account such as death certificates and liens paid back to Medicaid. The data were de-identified and aggregated by the accounting staff prior to analysis.

In order to characterize disbursement usage, the definition of each type of disbursement was reviewed to ensure that each category was as comprehensive and discrete as possible. For instance, tax preparation and payment of taxes were combined into one category, while landscape services, utilities and real estate closing fees were combined into housing sales services. The result of this review was 8 disbursement categories. These are:

- Funeral/Burial Planning: includes payments toward pre-paid burial expenses such as plot, service, headstone, etc.
- Housing Sales Services: includes payments toward preparing and selling a home, security systems, home maintenance, insurance payments.
- Medical Goods and Services: includes payments toward medical devices, medication, physicians, nursing, dental care, dentures, occupational therapy, physical therapy and ambulance services.
- Personal Needs: includes payments toward clothing, hairdressers, newspapers and other subscriptions, transportation that is not medically related, and car insurance.
- Professional Services: includes payments toward lawyers, financial advisors, and guardians.

- Social Support: includes payments toward elder care services and other paid companions.
- Tax Services: includes payments toward tax preparation and taxes.
- Telecommunications: includes payments toward telephone, cable, or other telecommunication services.

Once the eight disbursement categories were clarified, they were aligned with the 5 Gallup-Healthways well-being domains. This was done by applying the following decision rules:

- The items or services purchased within the disbursement category are directly represented by the well-being domain. (For example, a personal care assistant is a paid companion assigned to the disbursement category social supports; companions may escort the person to events and facilitate family contacts which therefore aligns to social well-being.)
- Each disbursement category is aligned to no more than one well-being domain.
- The majority of goods and services within a disbursement category support the well-being domain in which it is aligned, representing a "best fit." When a disbursement category supports, to a lesser degree, more than one well-being domain it was noted in the Discussion. This secondary alignment pertains to the categories community well-being, medical well-being, and purpose well-being and is discussed in detail in those sections of the discussion.

The alignment was done twice, once by the primary and secondary authors in collaboration and then a second time by an aging services professional. Prior to the independent alignment, the second coder was briefly trained on the exercise of matching categories to domains (rather than individual items). The reliability between authors and the second coder was 100%. Table 1 illustrates the resultant alignment.

This alignment shows that the well-being domains are supported by pooled trust disbursements. Only one domain of well-being, community well-being,

Table 1. Well-being domain alignment to pooled trust disbursement categories.

Well-being Domain	Pooled Trust Disbursement Category
Physical Well-being	Medical Goods and Services
Purpose Well-being	Personal Needs
Financial Well-being	Taxes
	Funeral/Burial Planning
	Housing Sales Services
	Professional Services
Social Well-being	Social Supports
	Telecommunications
Community Well-being	

was not supported by disbursements from the pooled trust. This exception may relate to the fact that the accounts reviewed in this study supported nursing home residents, for whom the facility *is* the community and is therefore paid for by Medicaid. Benefits that enhance the individual's experience within the community are captured as secondary alignments since the disbursements were deemed to better align to other areas of well-being.

In order to understand the impact of pooled trust funds supporting the well-being of individuals residing in nursing facilities, a literature review was conducted focused on the relationship between disbursement type and well-being domains on older adults, aged 50 and older. Since well-being has been defined in a number of different ways from broadly focused upon subjective happiness to more narrowly focused upon health-related quality of life, literature was selected only if it included similar constructs to at least one of the Gallup-Healthways domains of well-being.

Results

Of the five domains in the Gallup-Healthways paradigm, the one most frequently addressed by trust distributions was financial well-being (45% of funds). This domain incorporates disbursements for taxes (5% of total funds disbursed), funeral and burial planning (10% of total funds disbursed), housing services (14% of total funds disbursed) and professional services (19% of total funds disbursed). The next more frequently supported domain was physical well-being which accounts for 35% of the funds disbursed and is aligned to the disbursement category of medical goods and services. Together, supporting financial and physical well-being accounted for 80% of the trust funds disbursed. Purpose well-being and social well-being comprised the remaining 20% of the total funds disbursed. With disbursement for personal needs (11% of total funds disbursed) aligning with purpose well-being and the telecommunication disbursement category (2% of total funds disbursed) and the social support disbursement category (7% of total funds disbursed) contributing to social well-being. No disbursements directly aligned to community well-being, however, some disbursements categorized as medical and social supports secondarily aligned to this domain. Figure 1 shows the percentage of pooled trust funds aligned to each well-being domain.

Discussion

The distribution of the disbursements is heavily weighted toward financial and physical well-being, accounting for 80% of all disbursements. This may be a reflection of the concerns of individuals residing in nursing facilities, as they near the end of life. Alternatively, it may be that one disbursement category-taxes- the only one that is not optional, creates an artificial weighting toward

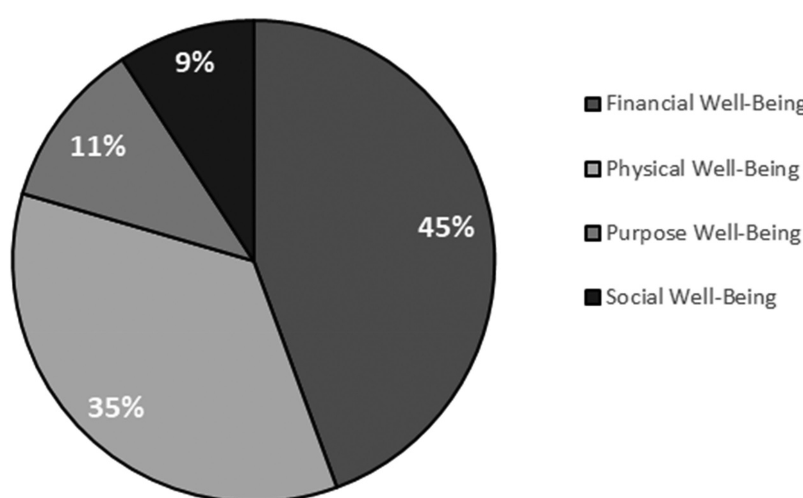

Figure 1. Percentage of disbursement funds in each well-being domain.

financial well-being. In order to check this, the tax disbursement category was eliminated and the distribution was recalculated. The result was very similar, with 44% of the funds aligned to financial well-being and 34% to physical well-being. Another explanation for the dominance of financial and physical well-being is that the requirements of the pooled trust create this bias. However, the broad requirements that the funds be spent only in supporting the individual and cannot be allocated to expenses already paid by Medicaid would not suggest that this be true, except in the case of community well-being discussed previously. Therefore, the distribution of funds to expenditures associated with financial and physical well-being do seem to be more of an artifact of the person than the pooled trust or nature of the disbursements.

Despite the dominance of financial and physical well-being, research suggests that for an individual to have a strong overall well-being, they require strong well-being in each of the five domains (Rath et al., 2010). In fact, the domains may be mutually reinforcing. A number of studies offer some evidence for this relationship. For example, in December 2019 a Gallup report found a positive relationship between income and health with people reliant on Medicaid and Medicare reporting significantly poorer health and emotional well-being than those who are privately insured (Saad, 2019). This reflects a relationship between physical and financial well-being. This is not surprising since the government insurance program, Medicaid, is specifically meant to support such individuals. Likewise, studies show that improved financial well-being, community well-being (Mather et al., 2017) and social well-being are related to positive mental health and overall health (Pinquart & Sörensen, 2000).

However, in a recent Gallup report (2019) physical well-being and financial well-being were noted to be most highly related to reports of general happiness and overall well-being. This is reflected in our analysis by the finding that 80% of the pooled trust funds purchased goods and services associated with supporting financial and physical well-being.

Well-being domains and their aligned disbursements

Our analysis of the disbursements suggests that individuals who reside in nursing facilities use their pooled trust funds to purchase goods and services that are aligned to the 5 domains of well-being. A closer analysis of each well-being domain and the disbursements aligned to them suggests the importance of these purchases.

Financial well-being

According to Gallup-Sharecare Well-Being Index (2018), a person experiencing financial well-being can manage their economic life in a way to reduce stress and increase security. Forty-five percent of all funds distributed supported financial well-being. Research shows a positive association between finances and well-being (Saad, 2019). For instance, a meta-analysis of 286 empirical studies of older adults found that socioeconomic status, particularly income, is associated with happiness (Pinquart & Sörensen, 2000).

Pooled trust disbursements afforded the opportunity to pay taxes (taxes disbursement category), cover funeral/burial planning expenses (funeral/burial disbursement category), access professional services (professional services category) and liquidate a home (home sales disbursement category). For example, Medicaid allows beneficiaries to prepay funeral expenses and to put aside money for additional expenses in a prepaid burial trust. A trust may not pay expenses after the beneficiary's death, and Medicaid eligibility rules limit the funds available for burial. The trust may, however, prepay funeral and burial expenses, with no financial limit. These disbursements therefore, may alleviate the concerns individuals have about placing an undue burden on loved ones after passing, providing peace of mind. Similarly, professional services that support financial well-being include the provision of guidance, expertise and assistance to beneficiaries in the management of their funds, ensuring timely payment of bills and safeguarding individuals' assets from fraud and abuse. The importance of these services is highlighted by studies that suggest that financial stress can contribute to depression in older adult populations (Alexopoulos, 2005).

Physical well-being

Gallup-Healthways (2017) defines physical well-being as having a sense of good health and enough energy to get things done on a daily basis. Expenses in this domain consisted of approximately one third of the funds distributed. The medical goods and services disbursement category includes purchases for specialized wheelchairs, eyeglasses, dentures, transportation to medical appointments and other medical services and devices not covered by Medicaid. As an insurance program, Medicaid does cover the majority of basic healthcare needs, however it may not cover specialized equipment or replacement equipment if a device is lost or broken before the person is eligible for a new item. Access to medical equipment and services provides comfort and pain management.

The importance of physical well-being appears straightforward: improved health and longevity. Indeed, the very definition of physical well-being includes a feeling of health. The correlation between health and physical well-being is one of the areas of focus in current research and literature. Research shows that people may experience physical ailments and still have a positive sense of physical well-being. The debate as to if health causes physical well-being or if well-being inoculates a person from poor health continues. Research is inconclusive as to the exact nature of the relationship between well-being and health. For instance, Steptoe et al. (2015) found that older people suffering from illnesses such as heart disease, arthritis and lung disease reported more depression and less happiness (which corresponds to overall well-being) and purpose (which corresponds to purpose well-being). But whether illness causes lower well-being or if lower well-being increases people's susceptibility to such conditions is inconclusive. Some studies suggest that well-being may have a protective role in health maintenance. Wikman et al. (2011) in the English Longitudinal Study of Aging, found well-being is associated with longer survival in people with chronic and terminal illnesses. Over a follow-up period of 8.5 years, 29.3% of people in the lowest well-being quartile passed away, compared to 9.3% of those in the highest quartile. This is supported by Diener and Chan's 2011 study found that it was not clear if happiness caused longevity for people with chronic or terminal diseases, but that happier people did live longer. While the exact relationship between health and overall well-being is not clear, the pooled trust disbursements associated with the physical well-being domain directly address health related needs and at a minimum enhance comfort.

Purpose well-being

Purpose well-being, according to Gallup-Healthways (2017), means that a person likes what they do each day and is motivated to achieve their goals.

Disbursements associated with this domain comprised 11% of the total funds disbursed from the trust. Liking what one does requires an action (doing) and implies that a person is able to interact with their environment and others. Therefore, disbursements aligned to this domain, the personal needs disbursement category, include expenses such as newspaper and magazine subscriptions, toiletries, incontinence products, snacks, dietary supplements, and transportation that is not medically related. These items and services provide a means to engage the environment and support access to activities.

The importance of having purpose is underscored by Musich and colleagues' (2018) study that found that in members of AARP, those with medium to high purpose in life used less healthcare, were more compliant to preventive services and reported a higher quality of life. Additionally, it was noted that purpose was associated with improved mental health and physical health outcomes. Other studies have also found that older adults with purpose in life are likely to experience less pain, less disability (Boyle et al., 2010), less dementia and Alzheimer's disease (Boyle et al., 2010), fewer incidents of stroke (Kim et al., 2013), fewer sleep problems (Kim et al., 2015) and reduced mortality (Krause, 2009). These findings suggest that trust fund disbursements that support individuals in engaging in activities that provide purpose to their lives may have a significant, positive impact upon certain potentially acute forms of illness.

Social well-being

Gallup-Healthways (2017) defines social well-being as feeling like you have supportive relationships and love in your life. Social well-being comprised 9% of disbursements from the trust. Funds disbursed from the social support and telecommunications disbursement categories were used to provide companionship, provide access to telephones and entertainment such as cable. Paid companions ensure that the individual is not isolated, may attend events and provides safety and oversight that may not be available.

Medical goods and services disbursements may also enhance social well-being to a lesser degree than physical well-being. These goods and services provide comfort as well as enable individuals to engage with their environment and other people. For instance, eyeglasses allow a person to read a book, enhance communication through reading body language, and facilitate mobility by allowing the person to see obstacles. Another expenditure that is crucial for facilitating nursing facility residents' ability to engage with their environment and others is hearing aids. Research has demonstrated that hearing loss corresponds to poorer communication and lower quality of life overall (Dalton et al., 2003).

Research has also demonstrated that improved social relations and social activities improve life satisfaction and well-being among older adults

(McAuley et al., 2000). Studies suggest that older adults with more social integration have less memory decline than those with little to no social contacts (Ertel et al., 2008). Additionally, nursing facility residents often describe their social interactions within the facility as insufficient for their needs, and companions help to fill that gap. Paid companions also relieve pressure on family members who may be the individual's sole visitor. Among Guardian Community Trust beneficiaries, some rely upon a sibling (or the case of extreme age, even a child) who is also an older adult and may have difficulty visiting frequently. Relatives who are younger may have to juggle competing time demands of work, care for children, and older adult parents. Trust disbursements routinely support social engagement by paying for companions to integrate the person into the facility activities, or just to visit. Such benefits play an important role in a person's functioning and well-being.

Other disbursements which support social well-being are those that afford non-medical travel, which are included in the personal needs disbursement category. For example, one beneficiary used money from the trust to travel to a grandchild's wedding, while another beneficiary used the trust to pay for a 90th birthday celebration. In one case, a beneficiary was living in a different nursing facility from his wife, who had different care needs. Because of this man's physical disabilities, he required special medical transport to leave the facility. Using funds from his trust, he was able to hire a medical transport company to take him once a week to visit his wife, whom he otherwise would not have been able to see.

Community well-being

Gallup-Healthways (2017) defines community well-being as liking where you live, feeling safe, and having pride in your community. In the analysis of pooled trust disbursements there were no clear expenditures that supported community well-being. There is research suggesting that people who are able to give to their communities are more likely to experience a positive sense of well-being (Tiernan et al., 2013). Therefore, if funds were used as charitable donations or to sponsor events within the nursing facility it would be reasonable to allocate those disbursements as supporting community well-being. However, monies from pooled trusts may be spent only to support the individual trustee, limiting the options to give to their community in a manner which requires funding.

This is not to say that community well-being is not important. In a review of the literature, Mather et al. (2017) found that while there are a number of confounding factors, older people's well-being tends to be more highly related to their community than younger individuals'. Yet, this research did not directly consider the well-being of older adults living in nursing facilities. Therefore, it is not clear the role of being in a nursing facility, with mitigating

factors such as the presence of friends, opportunities for engagement, and the individual's choice and autonomy, has upon well-being.

As stated earlier, community well-being is directly supported through Medicaid which funds the nursing facility. Issues surrounding the quality of the facilities and freedom of choice in facility selection and services are monitored and regulated by both federal and state legislation. As quality and choice improves, it would be interesting to monitor the relationship between these improvements and the community well-being of residents.

It is possible that trust disbursements indirectly support community well-being by enabling people to engage more fully in community life. Medical devices that support sight, hearing and mobility, while directly impacting physical well-being, may allow engagement in the community and increase a sense of safety. Additionally, social supports such as paid companions may also impact a person's sense of community well-being by increasing a sense of security and engagement in the community. Thus, while a pooled trust disbursement category may not be primarily aligned with community well-being, there may be indirect relationships.

Policy implications

When considering the quantification of the impact of healthcare, metrics often include health status, individual functioning, and cost. However, for individuals living in nursing facilities these measures, especially health status and functioning, are not an adequate reflection of the benefits of the healthcare received. Indeed, most individuals living in nursing facilities have poor prognoses and the expectation is a decline to death. Therefore, an alternative indicator of the benefits of healthcare services may be the well-being of the individual.

Health insurance programs do not proport, nor are they expected to, support all domains of well-being. As discussed above, there is an interaction between the five domains of well-being, with physical and financial well-being having a dominant role in an individual's overall happiness. Therefore, an insurance program which adequately and affordably covers health services is essential to the well-being of people who are dependent upon it, such as individuals who reside in nursing facilities. Yet, health services are not enough to adequately support well-being; other goods and services are also required.

Medicaid funds the health services for eligible individuals: those who cannot otherwise afford it. However, it falls short of covering all medical-related expenses and offers an extremely limited allowance, through the PNA, to support other needs, such as haircuts and telecommunications. Unlike social security, the PNA is not federally required to annually adjust for inflation, resulting in most states not having increased the PNA for a number of decades (Ortiz, 2009). Due to this failure to keep up with the

cost of living, individuals who are reliant upon Medicaid are less able now to afford basic goods and services not covered by Medicaid than when Medicaid last adjusted the PNA in 1987. State programs that are interested in supporting individuals' well-being, while being fiscally responsible, have the option of allowing special needs pooled trusts. A number of states do offer such trust programs, such as Kentucky and Massachusetts, however, it is not a national norm. Such trust programs relieve the financial burden to states' already stretched health programs, while offering a means of supporting the well-being of individuals living in nursing facilities.

As states envision regulations for pooled trusts, considerations regarding how the funds are spent may be guided by understanding their role in supporting well-being. For instance, disbursements that provide transportation that is not medically related seem especially poignant. Such opportunities increase access to the community as well as to people and events that have meaning to the individual. The ability to purchase preferred personal care items, watch a favorite TV show, buy favorite foods or have their hair done regularly may increase a sense of choice, decrease a sense of being institutionalized and enhance well-being. By offering the option of a pooled trust, states begin to address the gap between the cost of these items and what is currently afforded through the Medicaid program.

Limitations and considerations

This is a descriptive study which, as such, cannot assign causality or draw a conclusion regarding the nature of the relationships described. One potential methodological limitation is the influence of the accountants' categorization of the disbursements. The authors were not blind to these categorizations and were only able to access the assigned labels and amounts of individual disbursements- for example, a payment of 49 USD for telecommunications rather than 49 USD to a specific cable provider. This methodology does introduce several limitations. Firstly, it limited the ability to complete a sort by individual expenditure. It also limited our ability to use a more rigorous, empirical method to sort the disbursements into categories, for instance, through a principle component analysis. Hence it is possible if a more rigorous method was used, other categorizations and alignments may have resulted. It also introduces a lack of precision due to our assumptions regarding how funds were spent based on the financial office's descriptions. In the future, a prospective study that includes the use of the actual receipts rather than aggregated data would allow for a more empirical and detailed approach. However, this study does lay the groundwork for further investigations into the relationship between Medicaid, pooled trust programs, personal needs allowances and the well-being of older adults residing in nursing facilities.

Our discussion used research that focused upon older adults. However, the population in the literature varied from 50-year old's living and working in the community to those over 80 in hospice care. When possible, studies were used that focused upon adults, post retirement. There are a limited number of recent studies that focus primarily upon the well-being of older adults in nursing facilities. This suggests that understanding what contributes to the well-being of these individuals and the impact of well-being upon their lives requires further investigation.

Additionally, the definition of well-being varied greatly in the literature. Studies reviewed defined overall well-being as at a minimum, happiness. Most studies also included purpose and health as key constructs in their definition. Very few studies, except those completed through Gallup, used all five domains in their definition of well-being. Using literature that included at a minimum at least one Gallup-Healthways construct provides a more valid and cogent discussion and lends credence to the importance of pooled trust disbursements for individuals living in nursing facilities.

Conclusion

An analysis of one pooled trust's disbursement data suggests that the funds support the well-being of individuals through providing access to medical goods and services, social supports, professional services, personal needs, tax services, funeral planning, housing sales and telecommunications, which would not otherwise be available. These disbursements play an important role in supporting the well-being of individuals in nursing facilities by filling the gap between the goods and services covered by Medicaid, funds available through the Medicaid PNA and all the goods and services required to live life.

Key Points

- In some states, pooled trusts are exempt from the Medicaid financial eligibility requirements for older adults who reside in nursing facilities.
- The disbursements from pooled trusts may only be used to purchase goods and services not covered by Medicaid.
- An analysis of pooled trust disbursements suggests that the funds were used to purchase goods and services that support well-being.
- Pooled trusts offer a means for Medicaid programs to enhance the well-being of individuals residing in nursing facilities without increasing state funding of the personal needs allowance.

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