

ABCD Alliance for the Betterment of Citizens with Disabilities

Empowering People: Providers Shaping Policies

ABCD's Position on Contribution to Care and Maintenance

ABCD believes that there should not be any increase to the current 75% that an individual living in a community-based residential program contributes to their care and maintenance.

The Governor's budget includes a proposal to increase the amount of funds for Contribution to Care and Maintenance in residential settings from 75% to 100%. The proposal allows individuals to keep the \$100 a month of Personal Needs Allowance, an increase from the current \$40 a month Personal Needs Allowance.

Increasing the contribution to care and maintenance would impose a higher percentage on individuals living in residential settings than the average American spends on housing and food.

The federal government sets eligibility criteria for housing and has statistics related to the average expenditure for food. According to the Department of Housing and Urban Development, families who pay more than 30% of their income for housing are considered "cost burdened". According to the Department of Agriculture's Economic Research Service, Americans spend on average 9.6% of their disposable income on food.

ABCD understands that in many cases the entire cost of an individual's residential stay is paid by the State (some individuals pay their own rent and HUD subsidizes the costs). The federal government does not reimburse the State under the Medicaid waiver for Room and Board. However, taking additional funds from an individual who is living in the community for Room and Board leaves the individual with little to no money to fully participate in community life.

ABCD believes that an individual living in the community needs funds for general expenditures for living in the community such as medical (not covered by Medicaid or private health insurance), recreation, and personal belonging expenses. Increasing the percentage of funds for Contribution to Care and Maintenance up to 90% or more of an individual's income will leave them with no funds for community living.

Personal Needs Allowance (PNA) versus Contribution to Care and Maintenance

A PNA is set by the State for institutionalized individuals and couples whose care is paid for by Medicaid. A monthly PNA is money the individual or couple uses for clothing and other personal needs while in an institution, and is not considered income for the purpose of Medicaid paying for the cost of institutional care.

In New Jersey the Personal Needs Allowance (PNA) for people living in Developmental Centers and Psychiatric Facilities is currently set at \$40 a month and has not increased for more than a decade. For people living in rooming or boarding houses or residential health care facilities the PNA is \$89.50 a month and increase annually based on the Consumer Price Index.

Contribution to Care and Maintenance is generally a daily rate for the community residential placement of an individual with developmental disabilities. New Jersey developed a formula which assesses an individual up to 75% of their unearned income (generally SSI benefits) for the costs of care and maintenance. The regulations do allow an individual to retain more of their earned income from employment.

Difference between Institutional and Community Living

Individuals living in an institution live and reside in an enclosed setting where all the costs of an individual are paid for in an institution excluding haircuts, newspapers, etc.

Individuals living in community settings have the opportunity to participate in community life including recreational activities which cost money such as concerts, bowling, and other activities. In addition, the individuals must pay for a variety of items such as movie rentals, clothing, over-the-counter medications and other items.

Review of Items Individuals use 25% of their funds

ABCD requested information from its member agencies to determine the types and amount of funds which are spent each month by their residential clients. Interestingly we received almost identical lists of the type of expenditures from the different member agencies.

In general terms, consumers expend their 25% for medical, recreation and personal belonging expenses. They are summarized below:

1. Clothing and shoes
2. Medication and over-the counter medicines and doctor visits (co-payments for private insurance, unreimbursable medical/dental services)
3. Cable, long distance phone calls, internet fees, cell phones and movie rentals.
4. Personal items e.g. (toiletries, personal belongings, newspaper/magazine subscriptions, etc.)
5. Recreation e.g. (bowling, movies, community events, vacations, summer camp, etc.)
6. Haircuts
7. Personal gifts for family members and friends
8. Room upgrades – personalization of immediate living area
9. Food items not covered by operating budget and food at recreational outings including ensure, carnation, instant breakfast, preferred food items such as soda, and coffee.
10. Clothing such as boots, hats, gloves and summer apparel.
11. Additional bedroom furniture: chairs, desks, etc
12. Computer, I-pods, video games, etc
13. Saving for vacations such as camps which cost \$600
14. General shopping, crafts and going to the Dollar Store

An individual can easily spend a significant amount of funds, conservatively \$130 each month. For example:

- Haircuts average \$10-20 a month. For individuals with specific types of hair needs may have to spend as much as \$100 a month.
- Eating Out could cost as much as \$20-\$40 a month
- Art Classes average \$40 a month
- City Recreation program cost \$8.00 a month
- Other recreation another \$10 a month
- Snacks at work average \$20 a month
- Personal toiletries average between \$20-\$50 a month

What do other States do for Contribution to Care and Maintenance

It has been argued that New Jersey has one of the lowest rates for contribution to care and maintenance. However, based upon our review of state policies and correspondence with several State Associations we found that New Jersey currently has a rate which is similar to those in other states. The amount of funds vary in each State but individuals always are left with a reasonable amount of funds for their personal use. For example:

Indiana: An individual retains their full SSI check to use for their living expenses and personal needs

Pennsylvania: The provider can charge up to 72% of the SSI maximum rate for Room and Board.

Oklahoma: The provider can charge up to 90% of the average annual SSI benefit as long as the individual has \$100 left for individual needs.

New York: There is no percentage for contributions to care. The amounts allocated for personal allowance and billed for residential care are determined by a formula in State guidelines based upon type of residential program. The State has a personal allowance minimum of \$130-\$178 depending upon residential setting.

Conclusion

Individuals with developmental disabilities currently contribute 75% of their SSI and a portion of their wages (if working) for cost of care and maintenance.

Increasing the contribution to care and maintenance would leave an individual with little money to fully participate in the community with expenses such as recreation, everyday expenditures, and for medical expenses not paid for by Medicaid or private health insurance.

According to a recent survey of our member agencies, individuals spend as much as \$200 a month in personal expenses. An average individual can easily spend \$130 a month on community living expenditures.

Based on federal government eligibility requirements for housing and statistics for expenditures of food, Americans spend no more than 39.6% of their disposable income for room and board. Currently, New Jersey asks individuals to contribute 75% to their cost of care and maintenance (which is intended to pay for room and board).

ABCD reiterates its earlier calls to fully enforce the current regulations on Contribution to Care and Maintenance. A number of families are not providing the 75% of a person's SSI check for Contribution to Care and Maintenance. DDD should fully enforce this provision of the regulations rather than further increasing the percentage.