



Center for Disability Rights, Inc.

INTEGRATION, INDEPENDENCE, CIVIL RIGHTS

Community Supplemental Needs Trust

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Frequently Asked Questions

GENERAL

What is the Center for Disability Rights Community Supplemental Needs Pooled Trust?

Individuals with disabilities who have too much money to qualify for Medicaid can put the extra money into a special bank account called a Supplemental Needs Pooled Trust. The money put into this account is not counted as income or resources for people with disabilities applying for Medicaid and can be used for supplemental needs above and beyond what is covered by Medicaid.

The Center for Disability Rights, Inc. (CDR), a non-profit organization, has set up such a bank account, maintained by Canandaigua National Bank & Trust, allowing individuals with disabilities to qualify for Medicaid and still have the financial resources needed to live in the community. Although the funds are pooled together in the Trust, CDR maintains individual sub-accounts for each member.

Are trusts legal?

Yes. Trusts are used by many people as a tool to reduce assets so that they may apply for Medicaid. Supplemental Needs Pooled Trusts have been used for about 25 years. In 1993, Congress specifically authorized the use of Supplemental Needs Trusts. Although individual trusts are only available to those under the age of 65, CDR's Community Supplemental Needs Pooled Trust, authorized by 42 U.S.C. § 1396p (d)(4)(C), is available for people with disabilities of any age.

It seems odd that I would need to open a trust account and send you my money to then pay my bills. Can't I just pay my bills directly?

It may seem unnecessary, but those are the rules that the government set up for these trusts. If you didn't use the trust, those funds would have to pay for medical expenses for you to qualify for Medicaid. By putting this money in the trust, you get to use it for your personal benefit and still qualify for Medicaid. Although it may not seem like it makes sense, it is a tool to keep you at home and independent.

I heard that only people with developmental disabilities can use a trust. Is that true?

No. Although Supplemental Needs Trusts have been much more widely publicized within the developmental disability community as a tool to assist parents with getting Medicaid benefits for their developmentally disabled children, you can have any type of qualifying disability as long as your doctor has evaluated your condition and determined that you are disabled and you follow the Determination of Disability process.

Who would benefit by joining the trust?

Several different groups of people could benefit from joining this trust:

People who "spend down" to qualify for Medicaid. Some people "spend down" to get Medicaid services such as home care or other community-based long term services and supports because their monthly income or assets are over the limits established by the government to get Medicaid. Each month, these individuals need to pay for some of their own medical expenses and submit receipts or give the county a check. Instead, these individuals could put that money into CDR's Community Supplemental Needs Pooled Trust. Once the money is in the trust, it becomes exempt which means that it is not counted by Medicaid. The person becomes eligible for Medicaid benefits and services while still being able to use the money put into the trust for their personal benefit.

Families caring for a child with a developmental disability can use the trust for estate planning purposes. They can put money in the trust and use it for their child's future expenses. These resources will not prevent the child from qualifying for Medicaid.

People over the age of 65 can use this trust instead of paying a Medicaid "spend down." A Pooled trust is the only trust option for disabled persons over the age of 65 who have income or assets which are above the established Medicaid limits. It is an ideal solution for seniors who need long term services and supports, but wouldn't be able to maintain their home with the money Medicaid would allow them to keep. The trust allows them to do both!

People with brain injury or spinal cord injury - in fact any type of disability - who need Medicaid services to live in the community may benefit from joining the trust. This option allows folks to get the services they need without spending down virtually all of their money.

People with HIV/AIDS or other medical conditions that may have high medical expenses may benefit by joining our pooled trust. They can put money in the trust and use it for their future expenses. These resources will not prevent them from qualifying for Medicaid.

People on transplant list may be required to have Medicaid. The pooled trust allows them to qualify yet still pay any expenses not covered by Medicaid that they may have for the indeterminate period of time they are on the waiting list.

Are there any other advantages to being in this Pooled Trust?

Yes, as a member of the Pooled Trust the consumer is eligible to enroll in the Medicare Savings Program (MSP). This program assists the eligible consumer with paying for Medicare premiums, co-insurance, and deductibles. It is to the consumer's best interest to enroll in a MSP because it saves them a monthly amount of \$135.50 (in 2019) increasing their income which allows for payment for additional approved items.

ENROLLMENT

Do I qualify to participate in the trust?

You can have any type of qualifying disability as long as your doctor has evaluated your condition and determined that you are disabled. If you were born with a disability you may already receive Supplemental Security Income (SSI) or Social Security Disability (SSD) benefits. If you are over age 65 and have only received Social Security Retirement benefits, you may not have gone through the disability determination process. If you have not been previously determined to be disabled and you are applying for the first time, you must bring the Disability Determination Form and the Disability Interview Form to your doctor. Your doctor will use them to identify and document your disability. (CDR can provide you with these forms if you do not have access to a computer or you may come in to our offices and use our public computers.) After these forms are completed, you will take them to your Medicaid worker who will submit your application for public benefits.

These forms can be intimidating, especially if you are navigating through the process for the first time. If you need support with this process, CDR - or another partner Independent Living Center - can help you navigate this process. Information about our partner centers is available on the CDR website.

How much will it cost me to enroll in this trust?

CDR's Pooled Trust is the most cost-effective trusts in New York State. There is a one-time fee of \$200 to join CDR's Pooled Trust, which is taken from your initial deposit. If you receive Medicaid services through CDR or are transferring from another Pooled Trust, we will waive the enrollment fee. We also understand that for some people even \$200 can be difficult to pay, so if needed we will allow you to pay that over two months. Some other Medicaid providers or managed care companies have paid the enrollment fee for people as well.

After you are enrolled in the Trust, you pay a \$20 monthly maintenance fee, which includes up to four (4) withdrawals per month. If you require more than four (4) withdrawals for a given month, it will cost an additional \$10 for all additional withdrawals for the month. Annually, on January 15th, CDR will deduct a flat fee of \$50 from your trust sub-account to cover our independent audit. There are a few other fees for certain special requests.

How do I apply to join the trust?

You can contact CDR's Pooled Trust Department at (585) 546-7560 and a staff member will explain how the trust works and answer any questions you may have. Once you have decided that the trust is right for you or your loved one, you will need to complete a Beneficiary Profile Sheet and Joinder Agreement. The Joinder agreement must be notarized. You will also need to submit verification of your disability from Social Security or the Department of Social Services and verification of your spend down amount from the Department of Social Services. You will be required to send your first deposit of \$240 to initiate your trust sub-account.

Deliver or mail original completed Profiles / Joinder Agreements, the required documentation and your deposit to:

The Center for Disability Rights, Inc.
Pooled Trust Department
497 State Street
Rochester, New York 14608

You can also enroll in the Pooled Trust through Independent Living Centers that have partnered with CDR to facilitate your enrollment. Getting assistance to enroll in the Pooled Trust from these local, disability-led organizations is free.

Do I need an attorney to join the trust?

As with any contract, an attorney can help you understand the law. If you need help understanding your options, many Independent Living Centers offer benefits advisement services which help people navigate these complicated systems. Information on finding your local Independent Living Center is available on CDR's website.

What happens after the application is received?

A confirmation letter is sent to you from CDR. We will also provide you with a confirmation letter detailing your initial deposit, including all fees. Upon acceptance, you will receive a fee schedule, Disbursement/Withdrawal forms and a signed copy of your Joinder Agreement.

Will CDR notify Medicaid and the Department of Social Services when I am accepted?

Yes. We will send a letter to your County Medicaid worker confirming your acceptance into the trust (Be sure to include your worker's name and phone number on your

Beneficiary Profile Sheet). It is very important that these documents are received and processed by your Medicaid caseworker so that your participation in the trust is recognized. We also recommend that you call your Medicaid worker to make sure they got the paperwork.

DEPOSITS

After I am enrolled in the trust, how do I make my monthly deposits?

You send your payment to CDR every month. Although we encourage making a direct deposit, you can send us personal checks, money orders, cashier's checks or certified bank checks drawn on the beneficiary's account. Make them payable to CDR's Community Supplemental Needs Trust.

We do not accept cash. That's for your protection. If cash gets lost, there is no way to track it down. If you send a check and it doesn't arrive or gets misplaced (that happens very infrequently, but we are human), we can resolve the situation.

How do I set up an automatic payment into the Trust?

We encourage people to use direct deposit from your personal bank account because it is very simple. Once it is set up, you don't have to do anything until your spend-down changes.

The Trust has contracted with a third party software allowing us to automatically withdraw funds from your bank account. You authorize this process using the Pooled Trust Direct Deposit form. You simply fill out a Direct Deposit Form with your bank account information, the amount you want us to withdraw, and the day of the month to make the transfer. You can set up a regular amount to be withdrawn every month or authorize a one-time electronic transfer into your trust account.

How quickly are the funds deposited in my trust sub-account?

Our system is working around the clock. Scheduled electronic transfers happen overnight and are immediately credited to your account. Deposits that are mailed in are generally processed and credited the same day that they are received.

How accurate is your system?

We are handling money, so we put internal controls in place to ensure our staff process these transactions appropriately. Electronic deposits are verified by two people and can only be changed by a few staff. Our mail is opened by two people and the checks that are mailed in are documented separately to make sure nothing gets lost. The deposits are then credited to people's accounts by one staffer and then verified by a second. That ensures the highest level of accuracy.

WITHDRAWALS

When can I start requesting payments from the trust?

You can request payments from the trust as soon as the funds have been deposited in your account.

What is the process to get my bills paid?

You must submit each request in writing using our Disbursement/Withdrawal Form. You have to send complete bills with the disbursement form. You can send bills to us by email, fax, regular mail, or if it is more convenient and you live nearby, you can drop them off at our reception desk.

In order to pay a disbursement, the request must be approved by CDR's Pooled Trust Sub-Committee. They review and approve all your requests for payment. Once the committee has approved a payment to a vendor, that authorization is good for one year so we don't need to get repeated approvals and potentially slow down your payments.

Will you accurately pay my bills?

Everyone makes mistakes, but we have taken steps to ensure the highest level of accuracy. Most people don't realize it, but big companies – like your cable service – have a lot of different payment addresses for their customers. To ensure your bill goes to the correct address, we can only select vendors from your specific list. After your bill is input, just like we do with deposits, we have a second person verify the transaction information. The people who mail the checks (we still do that), also review the information, so your disbursement is reviewed by three different people.

How long does it take to process my disbursement request and pay my bill?

Our custom software is an extremely efficient system. Even with the verification of each transaction by a second person, disbursement requests are paid in about 2 days, assuming there are sufficient funds in your sub-account.

What happens if there isn't enough money in my account to pay a bill?

We input every disbursement request – even if there are not funds in the sub-account to pay the bill. If there are enough funds, the bill is immediately available to be paid. When there aren't enough funds, the bill is held in the system until you have the funds to pay it. These are "pending transactions". As an example, if we get the bill and input it when there aren't enough funds on Monday, the system holds it. At 1:00 AM on Wednesday if your electronic deposit is processed and credited to the account and it now has enough funds to pay the bill, your disbursement is released for payment and processed in the next check run.

What days do you send out checks?

Checks are processed every weekday, except for major holidays, and they are stuffed into envelopes and mailed so the bills go out into the mail as quickly as they can.

If you hold bills, can you hold a bill to pay it on a specific day?

No. We input disbursement requests as soon as we get them. If they are approved and there are enough funds, they get paid. We pay any bill that is in the system if there are enough funds and then in the order we received them. That means if we can pay a smaller bill – even if it came in later – we will pay it. You control the process by only sending in the bills you want paid.

I am concerned about the delay to mail the bill to CDR. Is there a way to make that happen faster?

You can fax or email your disbursements to us. You can also change your billing address with your creditors and have the bills come directly to CDR. If you have your creditors to send the bill directly to our office, the trust member's name must be on the bill.

If the trust can pay bills at different places, will CDR set up accounts for me?

We do not set up accounts for you because we are not authorized to make transactions on your behalf. A guardian or Representative Payee might do this, but they are legally empowered to do this. CDR is not.

It is also very important to us that we support your right to control your life. Our trust has been designed to give you maximum control over the funds within the law. You determine where the funds should go using a Disbursement Form. You can request that CDR's Pooled Trust pay specific bills, but CDR does not set up either corporate or personal accounts on your behalf. For example, the Pooled Trust may be used to pay your RG&E bill. The RG&E account is not set up by CDR for you. Instead, you set up your own account and forward the bills to CDR for payment.

Finally, CDR does not set up corporate accounts because we cannot assume liability for your transactions. CDR can make payments for you based on the funds you have available in the account, but we cannot be legally responsible for any debts you may incur. You can access the funds from the CDR Pooled Trust, however just like with a bank account you always need to set up your own arrangements with individual vendors.

I don't have a bill for my rent. Can you pay that?

Yes. You submit your Disbursement/Withdrawal Form and a copy of your signed lease agreement which indicates that you (the beneficiary) is the tenant. We can set that up as a recurring bill which gets loaded into the system on the same day of every month for up to a year. If you have the funds, the bill gets paid.

What do I do if my rent or mortgage is due on the first of the month but I don't get my money until later in the month?

The majority of members in the trust have us pay their rent or mortgage because it is a

big recurring expense. Most agencies have no problem with receiving the rent a few days past the 1st because most social security checks arrive after the 1st of the month.

That said, we do not pay a bill when there are insufficient funds, so budgeting for the payment is still your responsibility. You probably do this already if you get your money later in the month. You just make sure to save enough money in your bank account to pay for the next month's rent.

Some people are concerned that this is a hardship, but other trusts require the individual to leave a full month of deposits in the account all of the time. CDR allows you to have full access to your funds.

Can the trust pay a higher amount than what the bill is for?

No. The Trust can only pay up to the amount that the bill says you owe. We do this to ensure that there is not a possibility that for someone to go to the company and ask for a refund. This would result in having a higher allowable income for Medicaid than stated and could result in having to repay medical expenses covered by Medicaid that month. It could also endanger the trust and the other people who depend on it. We wouldn't do that.

Will the trust pay any bill?

Almost. The trust can be used for almost anything that enhances your quality of life without impacting Medicaid or public benefits. You can pay your rent or mortgage, utilities such as electric, gas, heating oil, telephone, and cable or satellite service. The trust can be used for clothing, food, or obtaining additional personal care or services not covered by Medicaid provided there is a bill or invoice.

CDR's Pooled Trust Sub-Committee will review and approve each withdrawal request on an individual basis. This Sub-Committee has absolute discretion to approve or deny withdrawal requests. Those are the government's rules. Your Master Trust Agreement details the responsibilities and authority of the Trustee. We can work with you to figure out how you can avoid denials and best get your needs met while still working within the rules of the trust.

My mortgage is paid. Can I pay my property taxes with the trust?

Yes. The trust can be used to pay property taxes.

Can I use the trust account to go on vacation?

Yes. You can use the trust to pay for vacation expenses for the beneficiary, including hotel, food, transportation, airfare, admission to events, parks, etc. If it is medically necessary, you can even use the trust to pay for personal assistance services while on vacation if Medicaid will not pay for them. Our CEO loves to tell the story about signing a check to send an elderly disabled woman and her attendant to Las Vegas for the disabled woman's vacation.

What can't the trust pay for?

Your trust is designed to enhance the quality of your life and allows you to pay for things that Medicaid does not cover. Purchases for things that are not considered to be part of a healthy lifestyle, are illegal or don't personally benefit the member cannot be paid for with funds from the trust. Expenses which cannot be approved from the trust include payment for the purchase of firearms, alcohol, tobacco, illegal drugs or drug paraphernalia. The trust also cannot pay legal fees related to illegal activities, restitution or bail. The trust also cannot pay for pre-existing credit card debt, fees associated with overdrawn bank accounts, debit card charges, or cash advances taken on credit cards.

Can I withdraw money from my account to use as cash?

No. Payments cannot be issued directly to you as the beneficiary. If we gave you cash that money would be counted as income for the purposes of qualifying for Medicaid and you would have to give it back to the Department of Social Services.

All payments must be made to third parties or vendors such as department stores, grocery stores or pharmacies. For example, if you wish to purchase a reclining lift chair for your home from a medical supply shop, we could pay the medical supply shop for you through your sub-account, using the invoice you provide with our Disbursement/Withdrawal Form.

Can I buy holiday gifts for my children or grandchildren or give a check to a family member as a gift from my trust account?

No. The trust can only be used for the benefit of the beneficiary. However, you can do whatever you want with the money that you keep to live on each month. Instead of using the trust to purchase holiday gifts, we would encourage you to pay allowable large monthly bills, like utilities, with the money available in the trust. Then you could use your own money to buy gifts. If you are concerned about having enough money during the holidays you could open a "Holiday Club" account with your bank or set aside money in your savings account to use for gifts for your family and friends.

Can the trust be used to buy gift cards for stores or restaurants?

No. Gift cards cannot be purchased with trust funds. The trust can be used to pay for lay-away orders at department and grocery stores or pharmacies as long as the purchase is for the beneficiary's use and it is not payable by Medicaid. Just keep in mind that although we will pay anything that's allowable under the law, the trust most efficient when you use it to pay larger monthly expenses, due to the administrative costs associated with making more than four withdrawals in a single month.

Feel free to call us with questions when you are not sure if an expense would be payable.

TRUST OPERATIONS

Do I receive statements for my CDR trust sub-account?

Just like a bank, you receive monthly statements from CDR's trust. Your statement will include a summary of all the activity in your sub-account for the month. These are printed on the same day of the month – the day your trust account was opened. So if your account was opened on February 14th, we would print your first statement on March 14th. Although we print statements every day, they only go out in the mail on weekdays.

You may need these statements for your annual recertification for Medicaid, please keep them in a safe place. You can direct us to send a copy to someone you designate who could hold them for you if you prefer. Upon request we will also send a summary of all deposits to your Medicaid worker at the time of your recertification.

Your statements give you more information than just your transactions. You can see the list of authorized vendors and the dates the authorization are good for. That way you can make sure to send in an updated Disbursement Request so we continue pay your bills without interruption. You also see the people who are authorized to access your account. That way you can make changes if you want.

I'm not sure if something was paid. Do I need to wait until I get my statement in the mail?

No. We have several options for you to manage your trust sub-account. First, we provide you with online access. Our website allows you to see all of the transactions on your account as well as see the authorizations, recurring payments and manage your account.

For people who want immediate information, you can also receive text alerts. We can send a text to a cellphone when your electronic deposits are scheduled, when deposits are posted, when your payment is entered in the system, when a payment that's been held is released for payment, and when the payment has been posted – which means we printed the check. You can choose any or none of these, and you can manage on our website.

Some people want to talk to a person to get their question answered, so you can call our customer service team and ask questions about your account. If our lines are busy, you can choose to leave a message and we will call you right back, or you can wait on hold. Our Customer Service Representatives can answer most questions about your account. They can see your entire account, can check our email account and faxes to verify that we have receive a disbursement request or other form. They can change your address or phone number and start or stop text alerts. Sometimes a question will require research.

They will "ticket" that issue to our accounting team, address the issue and call you back, although for complex situations that may take a couple days.

Will they talk to anyone about my account?

We will talk to anyone we are authorized to discuss your account with. Sometimes it can be helpful to have a family member or trusted friend assist with your account. You can authorize us to talk with them or change that at any time. If someone is not listed as an authorized representative on the account, we won't answer questions about the account. That means you control who has access to your information. So if we pay your rent and the landlord calls us, we won't talk to them, although we will be polite about that.

Because the purpose of the Trust is to help you qualify for Medicaid, we will communicate with the Medicaid office about your benefits without a specific authorization.

What if I go into a nursing facility?

This trust is for people in the community. Once you enter a nursing facility, you must stop making deposits into the trust. You may continue to request withdrawals from the remaining money in the trust until the account is exhausted. Once the balance is spent, your trust account will be closed.

My family is worried about a “transfer penalty” if I go into a nursing facility. What do we need to know?

If you are over 65, receive community-based Medicaid and participate in this trust, New York State has confirmed there will be no transfer penalty if you later enter a nursing facility. Transfer penalties had been a concern for persons over the age of 65 who placed their excess income into a trust and later entered a nursing facility. This is described in General Information System 2008 MA/020: Transfers to Pooled Trusts by Disabled Individuals Age 65 and Over, but in a nutshell, all the monthly deposits made into the trust were combined into a big penalty amount, which would disqualify the person from having Medicaid pay for nursing facility placement for a period of time. The period of time was determined by the total of the deposits compared to the cost of nursing facility placement. This period of disqualification was called the penalty period. This meant that trust participants over age 65 who entered a nursing facility would have been responsible to pay for the cost of their nursing facility placement for the entire length of this penalty period. That has changed!

The State Medicaid Program has confirmed that the use of pooled trusts by people over 65 will not automatically trigger the transfer penalty if they later enter a nursing facility. Please remember that in order to avoid any other penalties you must ensure that the money you place in the trust is spent on your monthly expenses. We urge you not to save large amounts of money in the trust or these unused amounts will be subject to a penalty if you later enter a nursing facility.

For example: You place your \$500 monthly spend-down into the trust for two years. Your deposits total \$12,000 and your total withdrawals from the trust each month for rent and utilities equal \$450 per month totaling \$10,800. The difference between your deposits and the total withdrawals made on your behalf is \$1200. If you entered a

nursing home, this \$1200 would be subject to the transfer penalty. To avoid the penalty, ensure that the money you deposit each month is spent on your behalf and do not allow it to accumulate.

Can I get my money back?

No. This is an irrevocable trust, so when you put your money in, it can't go back to you. We can use it to pay bills, but not give you – or anyone else – cash.

What if I move out of state?

This is complicated because every state has different laws regarding administration of public benefits. If you move out of state, you won't be able to make withdrawals from the trust until appropriate arrangements can be made. If you are planning to move, let us know so we can help you plan for these changes.

What happens if I decide to leave the trust?

You may stop contributing to the trust account at any time. If the beneficiary has a zero (\$0) balance for sixty (60) or more consecutive days, we reserve the right to close the sub-account. We must immediately report to your Medicaid worker that you are no longer participating in the trust as this may affect your eligibility for some Medicaid programs. If you decide to re-open the account, you may be required to pay any outstanding administrative fees stemming from the prior sub-account and you may also be required to pay a new enrollment fee.

What happens to my trust funds when I die?

Any money left in the trust at the time of your death will be used to further the purposes of the trust as indicated in your Joinder agreement. This means that no more withdrawals can be made after your death for any reason. That means we won't pay a bill after you died even if you incurred the expense before you died.

If you are concerned that there should be enough for your funeral, you can plan ahead for death and burial expenses. The pre-plan must be received by the trust before your death.

What kinds of things are those unused funds used for?

First, we use the funds to make your trust experience better. We have used these funds to custom code the software that has dramatically increased our speed and accuracy in processing transactions. (It used to take up to 10 days to pay a disbursement, and now we do that in less than three.) These enhancements included creating the options for online access to the trust, recurring payment processing, and text alerts.

Unlike other trusts, CDR is a disability rights organization, so we have used these funds to advocate on behalf of trust participants. Because of advocacy funded by the trust, we eliminated the requirement that members would need to verify their deposits every

month. Now this is only required in very limited circumstances. This has made the program easier for people to use.

We also developed a law to notify Medicaid recipients that they can use the Trust, so you may already have benefited from CDR's Trust when you were first told about this option. We also support other advocacy efforts to ensure Disabled and elderly people can live in the community.

It doesn't seem like CDR gets a lot of fees for doing this, so what does CDR get out of providing the trust?

CDR's mission is to work for the full integration, independence, and civil rights of people with disabilities. One of the most compelling reasons we decided to do this was some people have ended up in nursing facilities because they didn't have enough money to keep their housing after they qualified for Medicaid. This was particularly true for older women who were becoming more disabled. By making the trust available, seniors and people with disabilities have Medicaid services and the monthly resources stay in their homes.

When we started, our goal was to help a small group of people with disabilities live in the community. Today, over 6,000 people are in CDR's trust and CDR serves more than 10,000 people across the entire state.

What if I have more questions?

Call us at (585) 546-7560 and we will answer any questions you have about the pooled trust.

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