

Guide to Supports Available to Organ Transplant Recipients with Disabilities

People with disabilities can, with adequate supports, successfully manage post-operative treatment and stay healthy for many years after transplantation surgery. When evaluating an individual's likelihood of adherence to postoperative treatment, clinicians should consider (1) all present and future supports available to the individual, (2) whether the individual has a history of success at managing his or her treatment using existing supports, and (3) whether additional supports available to the individual could improve the individual's ability to manage his or her treatment.

The following sources of support may be available to help people with disabilities:

- Remember to take medication on time;
- Schedule and attend routine check-ups or transplant monitoring appointments;
- Monitor health status and signs of potential rejection or adverse reactions to medication regimens; and
- Monitor and manage care for other health conditions that may affect transplant success.

Source of Support	Examples
Family and Support Networks	<ul style="list-style-type: none"> • Parents, Grandparents, or other family members • Significant others • Friends • Community volunteers • Religious congregations
Medicaid-Funded Services May be available in the future even if the individual does not currently qualify for Medicaid (e.g., minors may qualify upon reaching adulthood)	<ul style="list-style-type: none"> • Personal assistance with managing medications, bathing, dressing, and maintaining a sanitary environment • Home health aides who can assist in medication management, monitoring health status, and providing skilled care • Case management, including ensuring that clients schedule and attend routine doctor's appointments • Teaching skills for independent living, including health and medication management • Respite care for times when caregivers need time away from administering care • Transportation to doctor's offices and other health care providers' offices
School-Provided Services May be provided through Individuals with Disabilities Education Act until student reaches age of 21, or through Section 504 of the Rehabilitation Act	Related Services during the school day: <ul style="list-style-type: none"> • Medication administration and monitoring • Skilled nursing services, including assistance with management of catheters, breathing tubes, colostomy bags Health Education and Transition Services: <ul style="list-style-type: none"> • Skills training in management of medications or other complex medical needs • Planning for health care management after transition to adulthood, including ensuring necessary supports are in place
Centers for Independent Living (CILs)	<ul style="list-style-type: none"> • Peer support • Independent living skills training • Information and referrals for community-based supports To find your local Center for Independent Living, visit http://www.ilru.org/html/publications/directory/index.html
Other Community Supports	<ul style="list-style-type: none"> • Protection and Advocacy Organizations (P&As) may provide assistance in securing necessary community-based supports • Long-term care insurance may help pay for necessary supports in managing health care • Private home health or personal assistance services, paid for out-of-pocket or through medical or special needs trusts To find your local P&A, visit http://www.ndrn.org/en/ndrn-member-agencies.html .

Planning for the Future

With responsible planning, people with disabilities may continue to receive support they need even after the people who now support them pass away or become unable to meet their needs. Examples may include enrollment in Medicaid home- and community-based services programs or creation of special needs trusts or financial plans to provide supports beyond those provided through Medicaid.

The absence of a fixed plan for ongoing appropriate support should not constitute a reason to deny a person with a disability access to transplantation, if they would be able to manage their post-operative care needs with appropriate support.

For more information, see Autistic Self Advocacy Network, “Organ Transplantation: A Guide for Clinicians”, available at autisticadvocacy.org/organs/.