
Independent Living Connections

Alert! Alert!

Because NICHCY's website will only remain online until September 30, 2014, most of its rich content has moved to a new home, the **Center for Parent Information and Resources (CPIR)**, where it can be kept up to date.

The new address of *Independent Living Connections* at the CPIR is:

<http://www.parentcenterhub.org/repository/independent/>

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Independent living is about life, isn't it? It's about choice, seeing to your own affairs, and pursuing your talents, interests, passions, and selfhood as independently as possible. We all would like to see our young people grow to adulthood and find their place in the world, doing for themselves to the best of their ability.

Disability can complicate independence, to be sure, which is why independent living can be an important part of helping a young person with a disability get ready for life after high school. The more involved the disability, the more likely it is that independent living will be a subject of serious discussion—and preparation.

This resource page is designed to help you and yours take apart the concept of independent living, examine its many elements, and put the concept back together again with concrete plans and insight into what it takes to turn the concept into reality.

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Philosophical Underpinnings

One search of the web using the term "independent living" and it's clear to see that a great deal of passion and commitment exists in the independent living movement and community. It's rather breath-taking, in fact. You'll see phrases like: all people achieving their maximum potential, barrier-free society, self-determination, self-respect, dignity, and equal opportunities, consumer-driven, empowerment. At its heart, the passion in the independent



living community is fueled by individuals with disabilities themselves. And it's worldwide, this passion for selfhood. Consider this statement found on the website of the Independent Living Institute in Sweden. It surely captures the point:

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own. We are profoundly ordinary people sharing the same need to feel included, recognized and loved.

You'll find this sentiment, this fierce independence, echoed in a thousand websites, brochures, training materials, and resource guides, because selfhood matters. We begin this resource page here, because the spirit behind the words above truly represents the hunger in us all to be ourselves and at the helm of our own lives.

With that in mind, let's have a look at the nuts-and-bolts of planning for independent living.

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Defining Independent Living

The National Secondary Transition and Technical Assistance Center (NSTTAC) posts the following definition of independent living.

Independent Living or life skills are defined as "those skills or tasks that contribute to the successful independent functioning of an individual in adulthood" (Cronin, 1996) in the following domains: leisure/recreation, home maintenance and personal care, and community participation.

So now we have yet more domains of adulthood, all these related to independent living:

- leisure/recreation
- home maintenance and personal care
- community participation.

Each of these, of course, has its own aspects and concerns that the IEP team will want to consider and plan ahead for, as appropriate for the student's needs and plans. We'll talk in a moment about what any one of these areas might involve, in terms of learning concrete skills. But first...

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Does the Student Need Transition Planning and Services in the Domain of Independent Living?

It's important to understand that not all students with disabilities will need an in-depth investigation of, and preparation for, independent living after high school. As the Department of Education stated in its Analysis of Comments and Changes (2006):

[T]he only area in which postsecondary goals are not required in the IEP is in the area of independent living skills. Goals in the area of independent living are required only if appropriate. It is up to the child's IEP Team to determine whether IEP goals related to the development of independent living skills are appropriate and necessary for the child to receive FAPE. (71 Fed. Reg. at 46668)

Whether or not will very much depend on the nature and severity of the student's disability. As the Department notes, it's up to each student's IEP team to decide if planning for independent living is needed. If the team feels that the student can benefit from transition planning and services in this domain, then independent living will be

an area of discussion during IEP meetings where transition is discussed.

If the student with whom you are involved is going to need transition planning and services in the domain of independent living, then keep reading. The remainder of this page concentrates on information and resources you'll find useful.

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What's Involved in Independent Living?

Independent living clearly involves quite a range of activities, skills, and learning needs. Consider just the three mentioned in the definition posted at NSTTAC: leisure/recreation, home maintenance and personal care, and community participation. Each of these can be broken down in its own turn to include yet more skills, activities, and learning needs. Just think about what's involved in "home maintenance and personal care" alone. Everything from brushing teeth to shopping for food to cooking it to cleaning up afterwards, to getting ready for bed, locking the front door, and setting the alarm clock for the next day. It's enough to boggle the mind, all the little facets and skills of taking care of ourselves as best we can, with support or solo.

So how is an IEP team to take on the task of planning for a student's independent living in the future? Much will depend on the nature and severity of the student's disability. Some students will not need transition planning or services to prepare for independent living. Others will need a limited amount, targeted at specific areas of need or interest. And still others, especially those with significant support needs, will need to give independent living their focused attention.

Fortunately, a great deal has been written about the skills of independent living, and we won't re-invent that wheel. Have a look at some of these resources. They'll more than give you food for thought about what to consider for yourself or yours, as will any local or state policy at work in your area.

Adolescent Autonomy checklist |

http://www.rockingham.k12.va.us/rcps_spед/svvp/Section%20VII/Adolescent-Autonomy-Checklist.pdf

How Minnesota approaches the domain of "independent living" |

<http://www.integratingstandards.org/dcd/index.html>

Assessing life skills | <http://www.caseylifeskills.org/>

Assessing students with significant disabilities for supported adulthood |

<http://www.ndpc-sd.org/documents/STSPI/2009/InstitutePresentations2009/ToolsforTransitionAssessmentforStudentswithSevereCognitiveDisabilitiesMorningstar.pdf>

Framework for Independent Living | Allegheny Intermediate Unit in PA

<http://www.aiu3.net/Level3.aspx?id=3602>

What the Mountain State Centers for Independent Living in WV have to say |

<http://www.mtstcil.org/skills/index.html>

The Arc's Self-Determination Scale | For youth with cognitive disabilities

<http://www.beachcenter.org/Books/FullPublications/PDF/TheArcsSelfDeterminationScale.pdf>

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Independent Living Centers (ILCs)

One of the most useful resources in the independent living area are the nationwide network of independent living

centers (ILCs). ILCs are nonresidential, community-based agencies that are run by people with various disabilities. ILCs help people with disabilities achieve and maintain self-sufficient lives within the community. Operated locally, ILCs serve a particular region, which means that their services vary from place to place. ILCs may charge for classes, but advocacy services are typically available at no cost.

To find out more about ILCs in your area, here are two national-level organizations that can put you in touch with state and local info:

Independent Living Research Utilization Project

(where you can find contact info for your Statewide Individual Living Council (SILC))

<http://www.ilru.org>

National Council on Independent Living

(to find contact info for local-level ILCs)

<http://www.ncil.org>

Visiting the websites of these two groups, or any of the individual ILCs in your state or local area will be a real eye-opener. You'll get an immediate scan of what types of services are available, what aspects of independent living you may want to consider when planning for your student, and much more.

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Other Resources To Explore

There really are too many organizations and associations to be fair about listing any. The ones we've identified below, listed in alphabetical order, will lead you into specific lines of investigation, such as the need for transportation, a personal assistant, a service animal, or other support for living independently. Pursue the resources that seem relevant to your student's needs and interests. There, you'll find links to many other organizations also interested in independent living, the participation of individuals with disabilities in community life, and the the self-determination to live life as fully and inclusively as possible.

Accessibility in parks, recreation, and tourism | National Center on Accessibility

<http://www.ncaonline.org/>

Disability.gov | Community living

http://www.disability.gov/community_life

Foster care | National Resource Center for Family-Centered Practice and Permanency Planning

http://www.hunter.cuny.edu/socwork/nrcfcpp/info_services/independent-living.html

Health issues | Disability.gov

<http://www.disability.gov/health>

Health issues | Adolescent Health Transition Project

<http://depts.washington.edu/healthtr/index.html>

Healthy living | Self-Advocacy Online

<http://www.selfadvocacyonline.org/learning/healthyliving/>

Home-based and community-based support | The Clearinghouse for Home and Community Based Services

<http://www.hcbs.org/>

Intellectual and developmental disabilities | American Association on Intellectual and Development Disabilities

http://www.aamr.org/content_117.cfm?navID=95

Personal assistance services | Center for Personal Assistance Services

<http://www.pascenter.org/home/index.php>

Recreation | The National Center on Physical Activity and Disability

<http://www.ncpad.org/>

Rural concerns | Association of Programs for Rural Independent Living

<http://www.april-rural.org/index.html>

Self-advocacy | KASA | Kids as Self Advocates

<http://www.fvkasa.org/index.php>

Self-determination | Center for Self-Determination

<http://www.centerforself-determination.com/index.html>

Severe disabilities | TASH

<http://www.tash.org>

Travel training | Easter Seals' Project Action

<http://www.projectaction.org/ResourcesPublications/TravelTraining.aspx>

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Which Transition Page Would You Like to Visit Now?

- [Main Transition Page](#) (Transition to Adulthood)
- [Transition Starters for Everyone](#)
- [Transition Goals in the IEP](#)
- [Students Get Involved!](#)
- [Adult Services: What Are They? Where are They ?](#)
- [Education/Training Connections](#)
- [Employment Connections](#)
- [Independent Living Connections](#) (you're here!)

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