Independent Living Connections

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.

**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 every-day 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.

**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 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…

**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 indepth investigation of, and preparation for, independent living after high school. As the Department of Education stated in its Analysis of Comments and Changes (2006):

[The 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 46068)]

**CONTINUED ON NEXT PAGE**
Independent Living Connections (continued from page 1)

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.

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 well any local or state policy at work in your area.

- Assessing life skills | http://www.casylefks.org/
- Assessing students with significant disabilities for supported adulthood | http://tinyurl.com/kja2lhd
- What the Mountain State Centers for Independent Living in WV have to say | http://www.mstcml.org/skills/index.html
- The Arc’s Self-Determination Scale | For youth with cognitive disabilities | http://www.beachcenter.org/Books/FullPublications/PDF/TheArcsSelfD.pdf
- 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. Oftentimes 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.illru.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.

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.

- Accessibility in parks, recreation, and tourism | National Center on Accessibility | http://www.nacoonline.org/
- Health issues | Disability.gov | http://www.disability.gov/health
- 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.ukas.org/index.php
- Severe disabilities | TASH | http://www.tash.org
- Travel training | Easter Seals’ Project Action | http://www.projectaction.org/ResourcesPublications/TravelTraining.aspx

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Promoting Independence in Early Childhood
“Self Confidence Encourages Independence” - by Debra Alcott, Early Childhood Specialist

When my son was three years old my husband and I bought him a plastic play-set with a slide. For weeks our son would climb all the steps and stop at the last one; at the top laid a gap wider than the rest of the steps, just before the slide. In order to slide down, he would have to use his arms to pull and wiggle until he could bridge the gap and slide down the other side. Watching his attempts to have the confidence of completing the task was an internal struggle for us as parents. We wanted to help him, but knew he had the ability within himself.

As parents it’s hard to let go and allow your child to try to do things independently. Often we do too much for our children because we want to shelter them, but by promoting independence in early childhood we are actually planting the seed of confidence that will grow and blossom with our children into adulthood.

Physical Independence – with a little thought, everyday routines can be transitional and teachable moments for children. To encourage physical independence you could try putting shampoo in a pump dispenser for easy use, placing markers and art paper in lower cabinets for easier access and picture labels on the inside to show where items should be replaced.

Setting an alarm or timer as a countdown for an activity to begin or end can also help guide children to be mindful and independent (e.g. iPrompts, stoplight clock, wait timer available on Google Play or the App Store).

Mental Independence –by promoting mental self-confidence we instill in children the courage to take risks. As parents, one of our best tools to achieve this is the use of praise:

Verbal praise is excellent in reinforcement, and ensures your child knows they have succeeded in a task. When using verbal praise, be sure to be specific in order to reaffirm your satisfaction with that responsibility. Instead of saying, “Good job” try “I like the way you put the paper and markers in the correct spot on the lower shelf”.

A smile, wink, head nod, or a thumbs up are all great examples of Visual Praise in action. Even refrigerator art serves as a constant reminder to the child that you enjoy his work well enough to display it to others and builds confidence in his ability.

Parents can also guide mental independence by simply asking questions – “What do you think we could do next?” Using the terms “we” instead of “you” makes the child feel he is working with you to find solutions instead of attempting the task solo. Slowly, over time as he becomes more of an independent thinker the terminology can change to “you”.

Allow Choice - Allowing a child choice gives empowerment in the decision making process by validating his opinions or feelings are important. For example: “Would you like to eat inside or outside?”

Remember, independence should be a gradual process and happen as your child matures and develops. The concept is to introduce and model the task, demonstrate doing it together and allow the child to do it independently. As parents, we are teaching the skill, not the perfect finished product. The idea is that your child is attempting the first steps to independence and should be encouraged along the way, before you know it, he will have reached the top, bridged the gap, and will be sliding down the other side.
Latino Corner

¿Has hablado últimamente con tu hijo acerca de su futuro?

Si ya está cerca de terminar la escuela secundaria, cuáles son sus expectativas y cuáles son sus sueños? Recuerda que el proceso de transición a la vida adulta e independiente comienza a los catorce años. No esperes a que llegue a la mayoría de edad sin haber planeado los pasos a seguir para que tu hijo tenga una vida productiva y satisfactoria.

Conversa frecuentemente sobre la seguridad, las situaciones de emergencia, los servicios a su alcance y las responsabilidades diarias.

Informate sobre las posibilidades para después de la escuela: la vida laboral, o la universidad o la formación profesional. Cualquiera de las posibilidades que tu hijo escoja necesitará de tu apoyo y tu ánimo. Ambos deberán tener en cuenta ciertas habilidades y destrezas que necesitará desarrollar para vivir en forma independiente.

- Manejo de dinero
- Uso de transporte público
- Problemas generales de salud
- Vivienda
- Compra y preparación de alimentos
- Higiene personal
- Responsabilidad en el trabajo: llegar a tiempo, expresar sus necesidades, trabajar en grupo, etc.

Mucho más forma parte del vivir diario, algunas habilidades simples y otras más complicadas. Pero lo más importante es la información y la discusión abierta acerca de dichos temas.

Tú eres el primer educador de tu hijo, en cualquier edad que este se encuentre. Prepárense juntos para esta última etapa que será la más gratificante de todas.

Have You Talked to Your Child About His Future Lately?

If he is close to finishing high school, what are your expectations and what are his dreams? Remember that the process of transition to independent adult life begins at fourteen. Do not wait until he reaches the age of majority to begin planning the steps for your child to have a productive and fulfilling life.

Talk frequently about safety, emergency situations, and services available and daily responsibilities.

Be informed about different possibilities after high school: working life, or college or vocational training. No matter what path he chooses he will need your support and encouragement. Both of you should be aware of certain skills and abilities that need to develop to achieve independent living:

- Money management
- Use of public transportation
- General health problems
- Housing
- Purchase and food preparation
- Personal hygiene
- Responsibility at work: be on time, express their needs, working in groups, etc.

Many more skills are part of anybody’s daily life; some are simple skills and some are more complicated. But it is important to be informed and to be open to discuss these issues.

You are the primary educator of your child, at any age. Get ready together for this last step that will be the most rewarding of all.

PEATC Workshops and Events 2014 - July 2014

**Wednesday, July 9, 2014 to Friday, July 11, 2014** – “Parents as Collaborative Leaders” Regional Training, Region VIII. Comfort Inn, 419 N. Agnew St. Burkeville, VA 23922. For more information or to apply, please go to: http://www.peatc.org/newsmanager/news_article.cgi?news_id=567&no_popup=0

**Thursday, July 10** – Saturday, July 12, 2014 – “Team Up! Virginia PTA 2014 Annual Conference” exhibitor, Richmond Marriott, 500 East Broad Street, Richmond, VA 23219. To register/for more information, visit the conference website: http://vapta.org/events/annual-conference.html.

**Tuesday, July 15, 2014** – “Understanding Special Education” workshop, 6:30 pm - 8:00 pm, at Columbia Grove Apartments, 1010 S. Frederick St., Arlington, VA 22204. Please register by contacting Wiaam Yasin at (703) 963-1632 or wiaam.yasinc@greenbrierlearning.org.

**Wednesday, July 23, 2014 to Friday, July 25, 2014** – “Parents as Collaborative Leaders” Regional Training, Region V. Location and time information will be provided to accepted applicants. For more information or to apply, please go to: http://www.peatc.org/newsmanager/news_article.cgi?news_id=567&no_popup=0
Promoting Healthy Independence
By Rhonda H. Pratt, Family Engagement Specialist

As parents we often wonder how and when is the right time to let our children go and grow. We struggle to find a balance between fostering independence while ensuring our children will always be here to support them should the need arise. In the midst of all of this are our hopes and dreams for our children’s future. As adults we understand the skills they will need to achieve success both personally and professionally. Therefore, it is our responsibility as parents to find balance and guide our children towards independence. Below are some suggestions for how you can foster healthy independence.

Independence at Home

Children are always looking to the adults in their lives for guidance and support while they seek opportunities to test out their own abilities and skills. Their ability to navigate life successfully will largely depend on the foundation that we lay when they are young. Therefore it is critical that we provide multiple opportunities for our children to develop their independence. Here are several examples of how you can promote independence at home. It can begin simply with the infant who is allowed to struggle to pull themselves up by grabbing a sturdy object in their attempt to stand for the first time. Or perhaps you permit your young child to make lunch for the first time even if it is just a peanut butter and jelly sandwich. Maybe you allow your 10-year-old to attend a friend’s sleepover. You might consider allowing your teenager to attend a school or community event with friends. There are so many ways adults can help children develop independence while still providing guidance and support.

Independence at School

As children enter the world of academics they must also make the transition from dependent to independent learner. For children with disabilities this can be a challenging time, but it is possible when we gradually allow them to be responsible for their own learning and advocacy. As parents it’s important that we look for opportunities in their natural environment. It’s good when parents are knowledgeable about their child’s disability and the IEP process. However sometimes we forget that it is just as important for our children to be educated about their disability and the IEP process. Each situation is unique and each parent must decide an appropriate time to involve their child in this complex process. It is beneficial for children to become active members of their team. This will better prepare them to advocate for themselves both in and outside the classroom. It looks like the young child who asks his teacher to reread the directions of a task or test or for a calculator to solve a math equation. It can also begin with allowing your child to attend their IEP meetings before the suggested age. Perhaps you have encouraged your child to write a letter to the IEP team explaining how he views himself as a learner and/or to share his hopes and dreams. Perhaps you share with your child a list of school clubs/activities and then allow them to choose one that they will participate in. Children are always looking for opportunities to demonstrate their independence. It is our responsibility as parents to help create those opportunities.

Independence in the Community

As parents we look forward to the day our child is prepared to go out into the world. However in order for them to be ready for that day they must develop both socially and academically. So you can help lay the foundation by beginning early. When you decide to take your child to the community playground, it’s important to allow them to decide whether and when they want to engage with other children or whether they want to ride the swing or the slide first. Perhaps you are planning a family outing; involve your child in the decision making process.

It's important that children believe that they have some control over their lives. When you allow them to make choices you give them the freedom they need to grow. You might be surprised at how providing such opportunities fosters independence. It is important that we begin early.

Special Resources for Special Needs - Independent Living

Community Supports: http://www.easyaccess.virginia.gov/community.shtml
Virginia Disability Services Agencies: http://www.vadsa.org/
Centers for Independent Living Listing: http://www.vadrs.org/cbs/cilslisting.htm
Centers for Independent Living in Virginia: http://www.accessva.org/CILAccessible.html
Virginia Commonwealth University (VCU) - Center on Transition Innovations: http://centerontransition.org/transition/independentLiving/index.html