# Tips for Developing Helping Your Child Develop Self-Advocacy Skills

The term "advocacy" generally refers to the process of trying to persuade others to support your position or point of view. Advocacy can take place in many contexts, both formal (such as in an IEP meeting, in a courtroom, or on Capitol Hill) and informal (such as when a teenager makes a case to his parents to be allowed to stay out late). Like anyone else, individuals with disabilities need to be able to speak up for themselves in order to express their wishes, wants and needs as well as to obtain the help and support of others, when needed. In other words, they need to develop and use self-advocacy skills. Depending on your child's age, this can mean anything from communicating his preferences at home (e.g. letting you know he'd rather have an apple than an orange for a snack) to letting an employer know that he needs a reasonable workplace accommodation (e.g., a change in workspace lighting). The following tips were compiled to help you and your child begin to navigate the process of developing self-advocacy skills.

# Tip One: Teach Choice-Making to Encourage Effective Decision-Making

Being able to recognize opportunities provided by others to make choices and initiate choice-making lays the foundation for independent living for all of us. Providing choices is clearly linked to improvements in self-determination and quality of life for individuals with disabilities. However, to be effective, the process of teaching independent choice-making to children, especially those with disabilities and/or more significant needs, must begin very early and must be something that is ongoing. Therefore, while much of the information that follows in this article may only apply to your child if s/he is in middle school or older, this tip is appropriate for children of *any* age.

Adults can begin offering simple, structured choices to children (even young children) by manipulating situations, tasks, or items already available at home, school and/or in the community. Making choices can give a child a sense of control over his or her daily activities. Children often resist activities or situations that they do not like and for which they have no control over the outcome. In contrast, an opportunity to make a choice may promote compliance in the specific activity, with the child influencing certain aspects of the activity. For example, embedding *choices* within daily routines such as the sequence in which required activities will be completed (as in "Would you like to brush your teeth before or after you take a bath?"), offering a choice of the time at which to begin a task that is required ("Do you want to go to bed at 8:30 or 8:45?"); and/or providing personal choice-making opportunities to your child (such as "Do you want to wear the blue shirt or the purple shirt?") can help the child practice choice-making. Notice that the choices initially being offered to a younger child are "structured choices"—they are between 2-3 mutually acceptable options. This will provide the child with frequent opportunities to refine his/her decision-making skills. Incorporating these kinds of frequent opportunities for the child to make even small choices about things that s/he is expected to do (i.e., choosing which task s/he wants do first, second, etc.)

can build independence, while giving the child a sense of control over things that occur in his/her environment.

For students who are approaching middle school age, it is important for them to begin to acceptable more responsibility for their behavioral choices. Presenting these children with a choice promotes behavior and values linked to responsibility. When they have a sense of responsibility, they can then be held more accountable for their actions. By incorporating frequent opportunities for choice-making into their day, both at school and at home, we can continue to build independence and enable the student to assume more responsibility for his/her actions and choices. Students at this age may especially enjoy making their own choices about when to stop or terminate a task that may not be their favorite thing to do.

Consider the example of John, a middle school student who does *not* like to clean his room. When asked to do so repeatedly, he will eventually "meltdown" into screaming at his mother until she concedes and says that he can do it later (but for John later never comes). Grandma is coming to visit and John's mother knows that she needs to prompt him to clean his room. This time she gives John a *choice* embedded in the prompt: "John, because Grandma is coming to visit, we both need to clean the house. While you clean your bedroom, I will clean the bathroom, but I thought it would be fun if you told us a time we should stop cleaning and take a break. I bought us ice cream sandwiches to reward our hard work. Let's see, it is 10 o'clock now – what time after 10:30 should we take a break?" At the time selected by John, his mother comes into his room with the ice cream sandwich and praises his hard work.

It is important to actively plan ways to teach choice making across all environments (home, school, work, community) by embedding frequent opportunities into the student's week. There are an infinite number of choice-making opportunities that can be offered at home to individuals with (and without) disabilities. They may include things like:

- choice of the *location* in which to complete a required task, such as homework (as in "Do you want to do your homework at the kitchen table or at your desk?");
- choice of the sequence or order in which required activities will be completed (as in "Would you like to brush your teeth before or after you take a bath?");
- > choice of the *time* at which to begin a required task; and/or
- personal choices such as the choice of what clothing to wear ("Do you want to wear the blue shirt or the purple shirt?").

Offering simple, structured choices like these to children of any age by manipulating situations, tasks, or items already available in the school, home and/or community provides the student with frequent opportunities to practice and refine decision-making skills. As our students with disabilities become older, this early practice at choice making will enable them to feel more comfortable expressing their preferences and making choices about larger issues such as future goals. Preparing your child to assertively and appropriately advocate for himself is an important aspect of transition planning.

# Tip Two: Facilitate Your Child's Understanding of His/Her Strengths and Preferences

In order for your child with a disability (or *any* child) to become a self-determined adult, that child needs to learn how to advocate for himself/herself and in order to do this, s/he has to be able to identify the positive qualities s/he possesses, his/her strengths, preferences, how s/he learns/works best, and what s/he needs to learn/work successfully. Your child will also need to understand his/her needs and be able to assertively and appropriately advocate for himself/herself, when necessary.

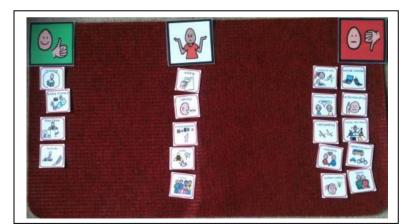
Once your child starts high school, throughout the school year it will be important to use a variety of activities, tools, and methods to try to assist the child in developing his strengths, interests and preferences related to his future. Adults should *avoid* waiting until an IEP meeting to identify this information with a child with a disability or attempting to elicit this information from him during a single, high pressure opportunity. One way to capture this information is to have the child help develop his/her own Positive Profile in which information such as strengths, interests, learning styles, needs, and future goals are represented. There are a multitude of resources for developing a positive profile, including those available through NJCIE at <a href="www.NJCIE.org">www.NJCIE.org</a>. Additional resources for developing and using a positive profile for your child are available at the following sites:

- http://www.spannj.org/START/Sharing%20Your%20Childs%20Strengths/Positive%20Student%20Profile.pdf
- http://www.positivepartnerships.com.au/learner-profiles
- http://ecacparentcenter.org/userfiles/PTI/Resource%20pages/Effective%20Communication%20and%20Tools/Positive%20Student%20Profile.pdf
- http://www.weareteachers.com/blogs/post/2015/07/27/begin-with-strengths-supporting-students-with-disabilities-in-the-inclusive-classroom
- http://www.pacer.org/webinars/planninginclusion/IntroducingYourChildtotheSc hoolCommunity.pdf

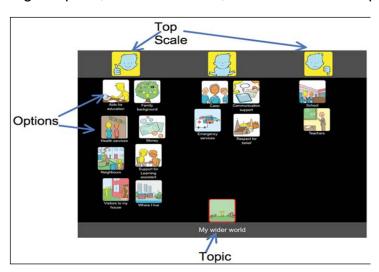
It is important to involve your middle school and/or high school-aged child in developing his/her own "positive profile". When creating the "profile", it may be helpful for you and your child to start discussing questions such as: "What are some words that describe you?", "What do you like about yourself?", and "What are some things you have done that you are proud of?". You may also ask your child to interview someone that knows him/her well (and whom *the student* selects) in order to gather information for this profile. If interviewing, it would be important that the interview questions be shared with the student in writing (possibly with picture cues, depending on the child's reading comprehension) and discussed ahead of time to clarify each item. The student could also complete a self-assessment (with or without the help of a peer or at home with a parent). An example is available at: <a href="http://knowyourskills.careers.govt.nz/">http://knowyourskills.careers.govt.nz/</a>. Many high schools routinely utilize these types of assessments with their students.

Be aware that making individual adaptations to measures that the school is using

for this may be necessary for your child with a disability. However, enabling our children with disabilities to understand and effectively express their preferences related to their futures



is extremely important, especially for children with more complex support needs, whose "voice" in personal choice-making is, unfortunately, not always given the weight it deserves. One strategy that can be used to support these individuals in expressing their preferences and feelings is to utilize "talking mats". "Talking Mats" refers to an interactive resource that uses pictures which students can place in categories to express their preferences. Talking mats consists of three sets of picture communication symbols ("topics", "options" and a visual "scale") and a space on which to display them. This display space can either be a physical, textured mat (see example right), or a digital space, such as a tablet, smart board or computer screen.



The "topics" symbols represent whatever you want to discuss (e.g., "what you want to do during the day", "where you want to live", "who you want to spend time with", etc.). The "options" symbols used relate specifically to each topic. For example, "What do you feel about going for a walk?" Or "what do you think about living at home?". The "top scale" allows participants to indicate their general feelings about each topic and option (see example left). The meaning of the

visual top scale can be adapted to suit the questions you are asking the person, such as whether they are happy, unsure, or unhappy. Once the topic is chosen, the participant is given the options one at a time and asked to think about what they feel about each one. They can then place the symbol under the appropriate visual scale symbol to indicate what they feel. Information about online training on talk mats is available at: <a href="http://www.talkingmats.com/training/">http://www.talkingmats.com/training/</a> Additional inforamtion and resources for using talking mats is also available at the following links:

- http://www.talkingmats.com/category/learning-disability/
- http://www.talkingmats.com/research-consultancy/free-stuff-communicationdisability/
- http://praacticalaac.org/praactical/talking-mats-a-praactical-tool/

# Tip Three: Help Your Child Understand and Express Supports Needed to Be Successful

Although entitlement to a free, appropriate public education under IDEA ends once your child graduates from high school or reaches age 21, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1974 prohibits employers and postsecondary schools from discriminating against an individual with a disability. Postsecondary schools and potential employers are required to provide appropriate adjustments as necessary to ensure that they do not discriminate on the basis of disability. However, to access these accommodations, your child will be responsible for self-identifying that s/he has a disability, explaining the disability and describing exactly what s/he requires as accommodations. In order to do this, the child will need to

understand not only his/her strengths, but also what kinds of supports s/he will need to be successful. Raising your child's level of awareness of his/her personal strengths, needs, and effective compensatory strategies helps position the child for a successful and independent transition into adulthood.

To accomplish this task, you and your child can beginning to create a lists of supports or accommodations that the child may need to access in order to be successful in a post-secondary educational and/or work environment. For high school age students, it may be helpful to visit the Job Accommodations Network (JAN) website (at: <a href="http://askjan.org/links/atoz.htm">http://askjan.org/links/atoz.htm</a>), which contains \information about supports available to individuals with disabilities in the workplace. The Job Accommodations Network website also includes lists of specific accommodations and supports arranged by a student's disability. For example, a list of possible work accommodations to consider for a student with a cognitive disability could be found at: <a href="http://askjan.org/media/intcog.html">http://askjan.org/media/intcog.html</a>. Items that may be included on a support list for a student with a cognitive disability might include things like:

- > posting written or pictorial instructions on frequently-used machines/devices,
- > providing written information on audiotape,
- developing written work agreements including clear expectations of responsibilities, and consequences of not meeting performance standards, and
- having the student view training videos to demonstrate appropriate workplace behavior and social skills such as where and when to eat at work, who to ask for help, what to do if you are mad, when to leave your workstation, etc.

After identifying the supports necessary for your child's success, these items can be added to the positive profile (see "tip two" for further explanation of the positive profile).

In addition to (or even as an alternative option), high school-aged individuals with cognitive disabilities who are investigating employment options and the supports which they will need to be successful in such endeavors may find "The I Want To Work Workbook" to be a helpful resource. "The I Want To Work Workbook" is designed to assist people with intellectual disabilities

My Support Page for Work  What people like and admire about Vicky:	
Nice manners	Friendly
Hard working	Always willing to help
Punctual	Compassionate
These are important to Vicky at work:  Having a schedule and a consistent routine  Drinking water throughout the day Being on time Dressing the way she is supposed to dress for work  To be around others	Instructions for supporters at work:  Giving Vicky clear, specific instructions Showing her how to do new tasks; break tasks into small step verbally and through demonstration Repeating directions Vicky needs water regularly because she dehydrates easily (gets pale & shaky). She takes responsibility for this. Advance notice, if possible, when a schedule changes It is helpful for Vicky to know who she can go to for help with directions or in case unexpected things happen. You may need to check on her periodically. Introduce yourself and ask Vicky questions to help her get to know you and other co-workers Ask Vicky if she needs help if she looks confused. Give Vicky regularly scheduled breaks and make it clear that breaks are to be used for snacks and bathroom. Vicky does better with choices rather than open ended questions

gather information that they can use to obtain employment. Completing this workbook will assist the individual in identifying areas of interest in which they would like to work, creating a "work support document" (see example right), and even generating a résumé. This resource can be accessed at:

http://personcenteredpractices.org/work\_workbook.html.

The development of a functional résumé, portfolio and vocational profile may also be helpful. Additional information on these can be found at:

- <a href="http://www.nj.gov/education/specialed/transition/VocationalProfile.p">http://www.nj.gov/education/specialed/transition/VocationalProfile.p</a>
   <a href="http://www.nj.gov/education/specialed/transition/VocationalProfile.p">http://www.nj.gov/education/specialed/transition/VocationalProfile.p</a>
- o <a href="http://personcenteredpractices.org/">http://personcenteredpractices.org/</a>
- o <a href="http://www.careeronestop.org/resumesinterviews/resumeadvice/sa">http://www.careeronestop.org/resumesinterviews/resumeadvice/sa</a> mplestemplates/functionalresumetemplate.aspx

After a support document including your child's strengths and preferences has been created, with needs and necessary supports identified and added, you and your child should develop a plan about how the child will obtain/access these supports. In order for your child to be able to gain accommodations that s/he may need to be successful in postsecondary life, s/he will need to be able to request them, when necessary. This might involve having your child become comfortable with sharing the support document (e.g., positive profile, work support page, functional resume, etc.) with others. Preparing your child to assertively and appropriately advocate for himself/herself is an important aspect of transition planning, so these type of self-advocacy and communication skills might need to be reflected in your child's IEP, so that progress in these areas can be tracked and reviewed regularly. Role-playing this type of conversation while still in high school may be helpful in preparing your child to do this after s/he graduates (whether at a postsecondary school or with a potential employer). Other self-advocacy links for students with disabilities that families can explore to assist with this process include:

- https://www.autismspeaks.org/family-services/tool-kits/advocacy
  This link allows you to download a pdf "toolkit" from Autism Speaks about self-advocacy and negotiation skills.
- http://www.fvkasa.org/index.php (KASA) Kids As Self-Advocates offers great materials to help with self-advocacy and communication skills.
- http://www.sabeusa.org/ Self Advocates Becoming Empowered (SABE) is the self-advocacy organization of the United States committed to full inclusion of people with developmental disabilities in the community throughout the 50 states and the world.

# Additional Resources for Teaching Self-Advocacy, Choice-Making and Related Skills

The following information has been adapted from:

http://www.nsttac.org/content/student-development-0. Each highlighted item is a hyperlink to a lesson plan or other resource for the selected topic. Right click on the highlighted item, then select "open hyperlink" to access.

Lessons for Teaching Self-Advocacy Skills:

- Help Recruiting Skills
   Balcazar, F. E., Fawcett, S. B., & Seekins, T. (1990). Teaching people with disabilities to recruit help to attain personal goals. *Rehabilitation Psychology*, 36, 31-41.
- o Social Competence Lesson Plan 40
- IEP Meeting Participation Using Self-Advocacy Strategy
   4\_7 37\_41

VanReusen, A.K., Deshler, D.D., & Schumaker, J.B. (1989). Effects of a student participation strategy in facilitating the involvement of adolescents with learning disabilities in the individualized educational program planning process. *Learning Disabilities*, *1*, 23-34.

### > For Self-Determination Skills:

- Self-Determination Component Skills <u>Lesson Plan 17</u>
   Abery, B., Rudrud, L., Arndt, K., Schauben, L., & Eggebeen, A. (1995).
   Evaluating a multicomponent program for enhancing the self-determination of youth with disabilities. *Intervention in School and Clinic, 30*, 170-179.
- Self-Knowledge, Communication, Life Skills, and Goal Setting Lesson Plan
   18

Fullerton, A., & Coyne, P. (1999). Developing skills and concepts for self-determination in young adults with autism. *Focus on Autism and Other Developmental Disabilities, 14*, 42-52.

Self-Determination for Secondary Students <u>Lesson Plan 19</u> Hoffman, A., & Field, S. (1995). Promoting self-determination through effective curriculum development. *Intervention in School and Clinic, 30*, 134-141.

#### > For Self-Awareness:

- IEP Meeting Involvement Using Person-Centered Planning <u>Lesson Plan</u>
   2 27 35
  - Miner, C.A., & Bates, P.E. (1997). The effects of person centered planning activities on the IEP/transition planning process. *Education and Training in Mental Retardation and Developmental Disabilities*, *32*, 105-112.
- Decision Making and Goal Setting Lesson Plan 25\_28\_36
   Phillips, P. (1990). A self-advocacy plan for high school students with learning disabilities: A comparative case study analysis of students, teachers, and parents perceptions of program effects. *Journal of Learning Disabilities*, 90, 466-471.
- IEP Meeting Participation Using Self-Advocacy Strategy
   4 7 37 41
  - (3) VanReusen, A.K., Deshler, D.D., & Schumaker, J.B. (1989). Effects of a student participation strategy in facilitating the involvement of adolescents with learning disabilities in the individualized educational program planning process. *Learning Disabilities*, 1, 23-34.
- Transition Planning Using Whose Future Is It Anyway? <u>Lesson Plan 30 34 38</u>
   Wehmeyer, M., & Lawrence, M. (1995). Whose Future is it Anyway? Promoting student involvement in transition planning. *Career Development for Exceptional Individuals*, 18, 69-83.

## > For Choice Making:

- Choice Making for Students with Disabilities
   Lesson Plan 20

   Browder, D. M., Cooper, K. J., & Lim, L. (1998). Teaching adults with severe disabilities to express their choice of settings for leisure activities.
- Choice Making in Residential Preferences Lesson Plan 21
   Foxx, R. M., Faw, G. D., Taylor, S., Davis, P. K., & Fulia, R. (1993). Would I be able to? Teaching clients to assess the availability of their community living life style preferences.
- Choice Making and Turn-Taking
   Sigafoos, J., Roberts, D., Couzens, D., Kerr, M. (1993). Providing opportunities for choice-making and turn-taking to adults with multiple disabilities. *Journal of Developmental and Physical Disabilities*, *5*, 297-309. Choice Making for Students with Severe Disabilities
- Choice Making and Turn-Taking Lesson Plan 24
   Stafford, A. M., Alberto, P. A., Fredrick, L. D., Heflin, F.J., & Heller, K. W. (2002).
   Preference variability and instruction of choice making with students with intellectual disabilities.
- Decision Making and Goal Setting Lesson Plan 25 28 36
   Phillips, P. (1990). A self-advocacy plan for high school students with learning disabilities: A comparative case study analysis of students, teachers, and parents perceptions of program effects. Journal of Learning Disabilities, 90, 466-471.

# For Goal Setting:

- IEP Daily Goal Attainment Lesson Plan 26
   German, S. L., Martin, J. E., Marshall, L. H., & Sale, P. R. (2000). Promoting self-determination: Using Take Action to teach goal attainment. Career Development for Exceptional Individuals, 23, 27-38.
- IEP Meeting Involvement Using Person-Centered Planning
   2 27 35
  - Miner, C.A., & Bates, P.E. (1997). The effects of person centered planning activities on the IEP/transition planning process.
- Decision Making and Goal Setting Lesson Plan 25\_28\_36
   Phillips, P. (1990). A self-advocacy plan for high school students with learning disabilities: A comparative case study analysis of students, teachers, and parents perceptions of program effects. *Journal of Learning Disabilities*, 90, 466-471.
- Transition Planning Involvement Using Take Charge for the Future <u>Lesson Plands 29 33</u>
  - Powers, L.E., Turner, A, Westwood, D., Matuszewski, S., Wilson, R. & Phillips, A. (2001). TAKE CHARGE for the Future: A controlled field-test of a model to promote student involvement in transition planning. *Career Development for Exceptional Individuals*, *24*, 89-104.
- Transition Planning Involvement Using Whose Future Is It Anyway? <u>Lesson Plan 30\_34\_38</u>
  Wehmeyer, M., & Lawrence, M. (1995). Whose Future is it Anyway? Promoting student involvement in transition planning. *Career Development for Exceptional Individuals*, 18, 69-83.

#### > For Problem Solving:

- Problem Solving to Complete an Independent Living Task

  <u>Lesson Plan 31</u>
- Problem Solving <u>Lesson Plan 32</u>
   Prater, M.A., Bruhl, S. (1998). Acquiring social skills through cooperative learning.
- Transition Planning Involvement Using Take Charge for the Future <u>Lesson Plan</u>
   3 29 33
  - Powers, L.E., Turner, A, Westwood, D., Matuszewski, S., Wilson, R. & Phillips, A. (2001). TAKE CHARGE for the Future: A controlled field-test of a model to promote student involvement in transition planning. *Career Development for Exceptional Individuals*, 24, 89-104.
- Transition Planning Involvement Using Whose Future Is It Anyway?
   Lesson Plan
   30\_34\_38
  - Wehmeyer, M., & Lawrence, M. (1995). Whose Future is it Anyway? Promoting student involvement in transition planning. *Career Development for Exceptional Individuals*, 18, 69-83.

# Additional Resources for Students with Disabilities Considering Post Secondary Options

Links to Assist Students with Disabilities and Families in Determining Options: <a href="http://www.ncwd-youth.info/411-on-disability-disclosure">http://www.ncwd-youth.info/411-on-disability-disclosure</a>

The National Collaborative on Workforce and Disability offers a guide to help students made decisions about when, how to disclose disability information as they move into life after high school.

# http://www.osepideasthatwork.org/toolkit/index.asp

Supported by the U.S. Department of Education, this site offers a free downloadable "tool kits" including: "Teaching and Assessing Students with Disabilities" and materials for parents, "on Universal Design for Learning".

#### http://dpi.wi.gov/sped/pdf/tranopndrs.pdf

The Wisconsin Department of Public Instruction offers a planning guide for life after high school.

Links for Students with Disabilities Considering College:

http://www.ed.gov/about/offices/list/ocr/transition.html

Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities - guide from the Office for Civil Rights.

### http://www.navigatingcollege.org/index.php

This is the site for the Autistic Self Advocacy Network. On the upper right side of the homepage is a link students can use to download a guidebook about transitioning to college. Each chapter is written by an individual with autism who has graduated from college; topics include how to manage dorm life and sensory regulation.

http://ldaamerica.org/rights-and-responsibilities-of-college-students-with-learning-disabilities-ld/

This links takes you to a pdf containing the "Rights and Responsibilities of College Students with Learning Disabilities (LD)

My Future My Plan: A Transition Planning Resource for Life After High School From the National Center on Secondary Education and Transition

# http://www.going-to-college.org/index.html

Website for students funded by a grant with the U.S. Department of Education, Office of Special Education and Rehabilitative Services. There are helpful tips and videos for students featuring actual college students with disabilities and a college planning timeline.

# http://www.temple.edu/studentaffairs/disability/videos/introducing.html

This video from Temple University features students offering advice on how and when to speak to professors about their disability and needs.

# http://myweb.wit.edu/counselingcenter/NCLD%20-%20Know%20the%20Differences.pdf

The National Center for Learning Disabilities offers a document on college transition that describes the differences between high school and college and offers suggestions to help students prepare for a successful transition.

## http://tucollaborative.org/pdfs/education/College\_Guide.pdf

This guide from the Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities provides a great overview of the postsecondary education options available to students and offers some helpful tips for how to manage themselves at college.

# http://www.usatoday.com/news/education/story/2011-10-17/college-and-learning-disabilities/50807620/1

This brief article covers some of the difficulties students with disabilities encounter in the transition to college—interesting mention about short "boot camps" held by Landmark College, which might be of interest to students as something to do over the summer.

### http://www.ldonline.org/indepth/college

LD Online, a great web resource, offers a variety of articles on transition to college, as well as recommendations for books and helpful links.

### http://www.ed.gov/print/about/offices/list/ocr/transitionguide.html

Transition of Students with Disabilities To Postsecondary Education: A Guide for High School Educators - pamphlet from the federal education department.