From deaf-blind to deafblind: Time for CDBS to make the change
By Maurice Belote, CDBS Project Coordinator

Summary: CDBS will be switching our terminology from “deaf-blind” to “deafblind” to better correspond with deafblind groups’ use of their own preferred terms.

Back in September 2009, I wrote a blog post on the CDBS website explaining why CDBS continued to use the term “deaf-blind” with the hyphen, while many others, including a few state deaf-blind projects, had switched to the unhyphenated spelling of “deafblind.” At that time, CDBS had decided to follow the lead of the American Association of the Deaf-Blind (AADB), which was the leading U.S. consumer group of individuals who are deaf-blind. The American Association of the Deaf-Blind is no longer an active organization, although we hope that with time it can spring back to life and continue the good work that it pioneered.

A new national organization—Deafblind Citizens in Action—has evolved that now seeks to become the national voice for teens and adults with deaf-blindness. Deafblind Citizens in Action (DBCA) seeks to increase awareness of deaf-blindness and promote legislation and public policy that promotes full integration into the broader society.

DBCA has chosen to adopt the term “deafblind” and explains their decision on the DBCA website:

DBCA doesn’t insert the hyphen. We also do not capitalize the “d” and “b” (i.e. DeafBlind). We believe it conveys the dual nature and recognizes it as a single, unified disability. We also champion the advancement of the entire worldwide community of persons with combined vision and hearing loss, and “deafblind” is more widely used around the world, which not only benefits Americans but also the entire world. [From the DBCA website: http://dbcitizens.org/]

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  - by Julie Maier, CDBS Educational Specialist
CDBS has always been committed to following the lead of deaf-blind consumers on issues related to self-determination, and rightful terminology is a core feature of self-determination. Therefore, beginning with this issue of reSources, CDBS will follow the lead of DBCA and adopt the term “deafblind.” All new written materials (e.g., technical assistance notes, articles, Facebook posts, etc.) will now reflect this. Changes to our logo, letterhead, etc. might take a little time to change and archived materials will reflect the use of “deaf-blind” as it was used at the time.

Comments? California Deafblind Services would love to hear from you! And check out Deafblind Citizens in Action and learn about the wonderful work they’re doing: [http://dbcitizens.org/who-we-are](http://dbcitizens.org/who-we-are).

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**The Power of Positive Interactions and Reinforcement with Children who are Deafblind**  
*By Stacy Aguilera, CDBS Educational Specialist*

Children who are deafblind need to gain a sense of success and be surrounded by positive experiences to feel empowered and reach milestones in their lives. Even as adults, if we lack confidence in a certain area of our life, we are less likely to venture into that realm. It is much easier to stay where we feel safe than to step out of our comfort zone and try new things. Multiple things have to be in place for us to do anything outside our comfort zone. The same thing applies to individuals with deafblindness. In this article, I will show how to create an environment that allows the space for a child with deafblindness to learn and grow using positive experiences and reinforcement.

Throughout my career in education, I have witnessed the power that comes from building children’s self-esteem using positive reinforcement and setting them up for success. When I first entered the classroom as a teacher for deaf/hard of hearing students after teaching general education, I noticed the lack of confidence my students faced on a daily basis. I often heard things like “I’m a loser,” “I’m stupid” and “I’m lazy”. My goal was to close the gap between where they were currently performing and their current grade level. It appeared to be an uphill battle because anytime I worked with them on reading, writing, math, etc. the tears would start rolling, and they would tell me they couldn’t do it and proceed to tell me how stupid they were or that they were losers.

Because they had already resigned themselves to failure in their own minds, I realized that until the students believed differently about themselves, it didn’t matter what they were taught. My number one priority became building their self-esteem and changing the way they described themselves.
We started off with positive things they could say to swap for the negative feelings from before. “I am smart” and “I can do it” became our new mantras. Along with the training and changing of the vocabulary we used, I set them up to perform tasks that I knew they would be successful at and praised them as they did it.

Learning became something fun instead of something scary. They knew they could trust me because I was consistent with presenting tasks to them they were successful at, using positive self-talk, and praise with everything we did. When I presented new tasks to them that would challenge their learning they never even realized it because we had already set the stage for them to succeed.

Within six months, these students progressed from being non-readers to having the ability to decode basic words. I was fortunate to have these students for three years of their elementary career in a regional self-contained classroom for children who are deaf/hard of hearing. The goal of the program at that time was to close the academic gap and get them back to inclusive educational placements in their home schools by the time they reached middle school. For that to happen, the students had to catch up on their academic skills and start mainstreaming before they were sent back. (Of course, inclusive placements aren’t dependent on being able to master grade level work, but this was my charge at the time.) By using the method of building their belief in themselves, they were able to do just that. By middle school, this group of students had become part of inclusive programs back at their home schools and no longer had to take what could be a two-hour bus ride to a regional program every day.

After my time as a classroom teacher, I then became an itinerant teacher and served multiple districts with students who are deaf/hard of hearing and part of full inclusion. The same principle of creating a positive environment to build self-esteem also applied to students I was working with in my new position. I had one girl that I worked with on communication weekly. She has CHARGE syndrome, and when I first met her she was not able to effectively communicate. She did use sign language, but she would only sign quickly and in front of her stomach where no one else could see what she was signing. This was another example of a student who did not have the confidence to communicate using the language she had learned. Instead, she resorted to pointing or waited until someone figured out what it was that she wanted or needed.

Her team and I worked on building her confidence surrounding her main mode of communication. It became an expectation that if she needed or wanted something, she had to sign it instead of pointing. At first, the child was unsure and was resistant to using sign language.
However, with consistency of expectations coupled with positive reinforcement every time she used signs to communicate, she began to feel safer using them. Everyone on her team and at home had to be consistent with our approach and expectations for this to happen. Now, three years later, this student is in middle school and plays in the school band. She no longer hides her hands in front of her stomach when she signs and she will even initiate conversations with those she is most comfortable with.

Three things had to occur in order for this progression to happen. First, she had to feel safe in her environment. Second, she needed to be guided to use the language with a lot of positive reinforcement. Third, there needed to be consistent expectations with all team members including family. The combination of these three things led to the child gaining confidence in a skill she did not believe she could do. When all these steps are in place, it sets the student up for success and then they will be more willing to step out of their comfort zone to learn the next step.

A child who is deafblind only experiences the world as far as they can hear, see, and touch. With limited vision and hearing, the size of their world can also seem pretty limited unless we act together with them to expand it. One thing we can do is create an environment that allows the space for them to learn and grow by using positive experiences and reinforcement. Listed below are the steps that should be taken to do so.

1. **Believe in their Abilities:** The first step is for both us and the child to believe they can learn. Do not limit what we think they can learn based on preconceived notions.

2. **Create a Safe Environment:** The child must then feel safe in his or her environment. This can be done by building a relationship with the student and gaining his or her trust. It is important not to exhibit frustration or negative feelings while you are interacting because children will pick up on these emotions.

3. **Consistent Communication and Environment:** There needs to be consistency in students’ environments with the people who are interacting with them, and the students need to be able to anticipate what is going to happen or come next in their day. This can be done by incorporating touch cues, name cues or name signs, and object or signed communication (depending on what the individual child needs) into their daily routines.

4. **Time for Processing and Transitions:** Children need to do things at their own pace. Most children who are deafblind need extra time for processing what is happening in their environments. There will need to be a beginning and an end to each activity, along with allowing time during transitions for them to process the next task. Transition time should be coupled with some sort of schedule that lets them know what the next task will be.

5. **Skills Practice and Reinforcement:** The child is now ready to learn and receive new input. Now that the child is ready to learn they need to feel successful at their current skill level. This can be done by learning what the child can do and creating a platform for them to perform.
the skill. During the practice of the skill and immediately following there needs to be positive reinforcement. This can be done in numerous ways depending on the individual child. Excitement and praise usually work well, along with learning what makes the child happy. If you don’t know yet what makes the child happy I would recommend asking family members because they know their children better than anyone else.

6. **Build on the Skills:** Once the child feels successful and is in a state of learning (not agitated, crying or sleeping) you can start introducing the next level of the same skill they were successful at and build on their prior experiences. Some examples are:

**Example 1:** If the child has mastered matching identical objects and has almost mastered learning how to match similar objects, the next step could be washing and sorting forks and spoons of various sizes used at snack and lunchtime and putting them in the appropriate containers. Not only does this build on their previous skill set, but it also gives them functional skills that will lead to independence.

**Example 2:** The child learned how to walk from point A to point B with guidance. The next step would be to let the child lead you to the destination they have learned. This can be done in stages (i.e., the first stage would be they walk outside the classroom door and give them time to determine which direction they start out—left, right, or straight).

7. **Keep it Up:** Continue creating a space of positive experiences and building on skills using positive reinforcement and consistent expectations and communication.

By continuing to create this space of positive experiences, it makes learning easier for the student, and they don’t realize they are being asked to do a task outside their comfort zone because it happened gradually at his or her pace. Setting children with deafblindness up for success empowers them because they will believe in themselves.

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**Defy Limitations**

During this past year’s CHARGE Syndrome conference, we were all reminded about expanding your horizons and not settling when it comes to potential. A speaker with CHARGE syndrome said: “*Don’t tell me the sky is the limit when there have been people who walked on the moon.*”
Letting go to let them Grow: Teaching Independence
By Myrna Medina, CDBS Family Specialist

When we parents think about our children being independent, we may picture them as all grown up in a happy life, with us hoping that they will find a good job, be part of a community, and maybe even get married. When looking at this future picture, it may seem like “independence” is an event that happens down the road. The reality is that we have already been promoting their independence from a very early age without realizing that we have started the process of letting them go.

Some examples of early independence-building activities are: playing peek-a-boo (covering your face and pretending to disappear), playing chase around the furniture, allowing other adults like grandparents or babysitters around them to care for them, letting them sleep in their own crib or bed, and the very important step of having them attend school. These kinds of activities and opportunities allow your child to understand that you are there for them even when you are out of sight, and to eventually learn that even when you are not there, they will be okay. Although this may seem easy to do in theory, parents of children with special needs often find the process of letting go and allowing their children to become independent to be difficult and stressful, and often filled with serious concerns.

If I think back to when my son Norman was much younger, many service providers told me that we had to set goals and work on different activities to maximize his potential to become as independent as possible. Some areas we worked on were communication, motor skills, independent living skills, socialization, and many more disciplines. But who would have thought that this learning process related to independence was working in both directions? It was helping Norman reach his potential and it was gradually helping me—as a mother—with the process of letting go. I had not realized until later in life that all this hard work had also played a significant part in my own preparation (process) of letting go and promoting Norman’s independence to adulthood.

Parental Concerns

It is difficult to process that most likely my little Abby will not outlive me. Even now, I see her little fragile body weakening. I often find myself trying to cram in as many memories as possible into our lives. At this point, she has started having seizures and for that reason alone, she sleeps with me every night. I will be my Abby’s BFF and I refuse to not enjoy every moment of her life with her. Let’s face it - she is stuck with me.

~ Abby’s mother

Thinking back to my own experience with this process, I can say with certainty that it has not been easy. There have been many factors that have impacted, influenced and even interfered in the process. Fear can also keep you from starting: fear of the situation your child is in, fear of the unknowable future, and even the fear of parents that by moving towards independence, your child may no longer need you in their life as much.

The following two columns describe how these factors and challenges affected my processes but also will demonstrate some ways that I cope and overcome them:
<table>
<thead>
<tr>
<th>Factors</th>
<th>Coping Strategies</th>
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| **Medical Issues**  
Having a medically fragile child dependent on medication and needing medical equipment handy at all times has been emotionally difficult for our family to overcome. Norman’s health and well-being have been our number one priority. | Getting as much information about his medical condition and treatment as possible, providing all the medical care Norman needs, and attending all medical appointments and therapy sessions definitely help us ease this concern. Learning as much as possible and knowing we are doing everything we can has been important in coping. |
| **Special Needs Challenges**  
Accepting and understanding Norman’s disabilities has been an ongoing process. As a parent I could not avoid thinking how these weaknesses impacted his life, from playing, learning, self-help skills to be fully independent, etc. | We’ve used many strategies: learning to look at Norman’s strengths vs. his challenges, celebrating his successes, supporting him doing things instead of doing them for him, and encouraging and teaching him to express his wants and need to the maximum extent, so that he can be as independent as possible. |
| **Anxiety, Fears, and Stress**  
Having dealt with medical and special needs issues, it was nearly impossible not to add anxiety, fear and stress to the list of concerns: anxiety of the unknown about his health condition, fear that something will happen to him if we were not there, not knowing what to do in case of a medical crisis, and the stress of separation. The sense of security and protection we feel when he is with us was acting as the biggest obstacle to letting go that we as a family continue to manage. | This is an on-going process. I started to let go of him little by little, allowing gradual separation from the beginning. Making sure that all his needs were met and that an action plan was in place in case of an unexpected difficult situation would definitely help ease the separation. |
| **Cultural Beliefs and Family Dynamics**  
Our family values, traditions, norms and customs sometimes are a kind of barrier or obstacle in the process of letting go and in fostering and encouraging independence, from seeing disability as an illness to the belief that parents should assume all responsibilities for the care of our child. Our family culture shapes how see the world, our personal values and our attitudes, including perceptions and expectations on what works and what doesn’t work. | Allowing my family to be Norman’s primary support group, and by letting us be part of Norman’s education, medical and social life has helped us all perceive his condition more openly and from different perspectives. We each have a better understanding of his condition and the way we look at Norman’s strengths and challenges. |
### Factors

#### Over / Under Protection

There is definitively a very fine line that is very hard to distinguish between over-protection and under-protection. On one hand, as a parent you want to provide and respond to all his needs to allow him to live a good healthy and happy life. On the other hand: you want to promote a healthy independent life as much as possible. This has been a battle that I have to fight all the time, the sensation of mixed emotions between separation, safety, abandonment, neglect and overprotection.

As parents, we have to trust our instincts and follow them the best we can. We have to be aware and accept our feelings and emotions that many times do not have to do with our culture. It has more to do with the parent’s natural fear to detachment from their child. Knowing that these feelings are normal and that we still have to allow for independence can help a little when we have the chance to step back and think about the situation.

### Coping Strategies

Not all of the above factors, concerns, and challenges apply to every family and their child with special needs. Below are some strategies that might help in many general situations:

- Learn about your child’s medical condition, diagnosis, prognosis, treatment etc.
- Understand your child’s disabilities/challenges and focus on their strengths instead of thinking about what they can’t do.
- Pay close attention to what the child can do independently in order to balance the amount of support needed.
- Gradually separate from your child.
- Recognize how much separation or closeness they need and can tolerate.
- Participation in their educational plans will give you some control over whether or not their needs are being met.
- Help your child learn how to maintain connections to others.
- Although your “protector instinct” is always there, encourage your child to try things themselves first before offering your help.
- Encourage self-determination (check out this resource on self-determination from NCDB: https://nationaldb.org/library/page/2038)
- Understand the importance of transitions (check out CDBS Fact Sheet #35: http://www.cadbs.org/fact-sheets/)
- Treat your child according to his or her age.
- As much as possible take the role of consultant instead of decision maker (offer help so they can make decisions).
- Set expectations of helping at home (like chores) as with any typical child.
- Use respite care or any other care service to allow both of you some separation and time apart.
- If there are siblings, encourage positive sibling relationships.
- Participate in personal future planning and talking about goals and how to reach these goals.
- Financial planning: think about a special needs trust, Medicaid, SSI, etc.
- Don’t rule out possibilities for your child such as work, college or living independently.

And finally, on a personal note: **Start early.** Don’t wait until your child is almost an adult to act. Promote healthy independence as early as possible.
“The changes I have noticed in my program before and after running student led IEPs and involving students in their goal monitoring have been huge! Our program outcomes are so much more comprehensive and successful because we involve our students in the creation and implementation of their educational programs. My students understand that success is a process and not a product.”  
~Alyson Furnback, teacher of transition-aged students

Summary of article: Our last reSources newsletter included an article describing a student-directed IEP approach. In the article I shared my recognition of the value of this process for students, as well as for participating educators and families. The article discussed the importance of preparing and supporting students to participate as fully as possible in all parts the IEP process including assessment and planning, leading and/or contributing to development of the IEP at the annual meeting, and meaningfully participation in implementing and evaluating IEP goals and progress. I also discussed how this approach is new to many teams and families and included a list of suggested ways families and educators can work together to support a student to take charge of the IEP process. The article also offered insights from actual teachers, parents, and students related to their transition to the use of this approach and the positive outcomes they have encountered from utilizing a student-directed IEP process. This second article digs into some specific topics, tools, and strategies that can support your efforts to prepare students to participate in assessment and drafting of individualized goals, participation in their IEP meeting, and self-evaluation of their goals and progress.

In the previous article I wrote that the Individualized Education Program (IEP) process is not just a single meeting held once a year, but a process that includes three important phases: 1) assessment and planning; 2) leading and/or participating in meeting to review progress and develop future goals and support plans; and finally, 3) implementing and consistently evaluating IEP goals and plans. In a student-directed IEP process all of these phases are still integral and students can participate meaningfully in each phase with careful planning for their individual instructional support and accommodation needs. I’d like to now describe steps and strategies you can use in each phase using a student-directed approach.
Assessment and planning
To successfully direct or lead the IEP process, students will benefit from information about the following: 1) the reason and purpose for an annual meeting to discuss progress and develop educational goals; 2) the assessment process; 3) elements of a typical meeting; 4) and importance of regularly evaluating progress on goals.

Many students recognize their annual IEP as a routine in which teachers and other specialists take them out of class or away from a regular class activity to work on tests, tasks, and skills that are not part of their typical school routine. They may think the meeting itself is long and boring and not important or relevant to their lives. Many students don’t recognize how the IEP process is connected to their vision of their future. I am encouraging you to think differently about this process and consider how much more meaningful the development, implementation, and evaluation of the student’s goals and progress will be if student is involved in identifying their skills, areas of needs, supports and accommodations, and progress with a recognition that the IEP process is helping them prepare for their future.

What’s my first step?
First let’s think of the need for information to understand the process. What are some topics in which students might need information? Here are some topics to consider:

- History of special education services and law and key elements of IDEA including FAPE, supplementary supports and services.
- Explanation of the acronyms associated with IDEA and IEP
- Student’s and parent’s legal rights within IEP
- Purpose of assessment, types of assessment and reporting of assessment
- Components of the IEP document and typical agenda of an IEP meeting
- Who attends the IEP meeting and why
- Developing draft goals and writing IEP goals
- Ways to measure progress and evaluating progress toward meeting individual goals
- Types of accommodations and supports
- How to advocate for your rights and for necessary supports and accommodations
- Ways to share information about yourself, your goals, and support needs with others

How can you share this information?
I have seen teachers use curriculum they have personally developed as well as curriculum available on websites or in commercial curriculum (see Recommended Resources page included at end of Part One article in reSources Summer 2015 issue - http://files.cadbs.org/200002551-293ef38dd/1reSourcesSummer2015.pdf). Teachers have found success when providing information using simple text, visuals, and tactile concrete examples via PowerPoint or Prezi presentation or posters. They often adapted the material to meet the needs of their students including the use of less text and simplifying language for some students, adding picture icons or photos, and showing actual samples of the material they are presenting (e.g. a completed IEP document, sample IEP goal, a poster listing student’s IEP rights or types of support and accommodations, photos of the people who will be attending the meeting, a picture icon that represents different parts of the meeting, a sample goal tracking sheet for evaluation).
Grouping arrangements for presenting this information and preparing students for their IEP meeting vary. Most teachers I know find it most effective to regularly schedule a period to work with either small groups of 2-4 students or individual students. The small group format can be useful for presenting information about the topics listed above. Both small group format and 1:1 instruction will likely be most effective with students with deafblindness due to their need for direct instruction and use of assistive devices and other adaptations. Individual sessions are the best format when looking at assessment results, deciding what information the student wants to share and how the student will share information with the team, and developing draft goals to present at the IEP meeting. The chart below includes suggested considerations during this planning and preparation phase for a range of students based on their level of support needs (minimal, moderate, and higher).

### Supports and Adaptations to Consider during Planning & Preparation Phase

<table>
<thead>
<tr>
<th>Preparation Area</th>
<th>Students with higher support needs</th>
<th>Students with moderate support needs</th>
<th>Students with minimal support needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparing student by providing information</td>
<td>Use picture icons and photos of real life events and people.</td>
<td>Use simpler, clearer language &amp; explain terms, concepts related to process.</td>
<td>Allow student to use any accommodations necessary and present in language format they are most comfortable.</td>
</tr>
<tr>
<td>Adapting level of content for student</td>
<td>Use basic terms that are relatable to own life.</td>
<td>Provide all information in clear simplified language with visual or tactile examples.</td>
<td>Explain acronyms and jargon associated with IEP.</td>
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<tr>
<td></td>
<td>Use visual and tactile concrete examples.</td>
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<td>Share links to resources and services where more information is available.</td>
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<td></td>
<td>Break lesson into several parts.</td>
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<td></td>
</tr>
<tr>
<td>Encouraging student participation during lessons, and preparation for meeting</td>
<td>Provide opportunities to make choices from a limited range of options.</td>
<td>Provide choices.</td>
<td>Offer suggestions or hints to student to encourage sharing of ideas, goals, desires.</td>
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<tr>
<td></td>
<td>Offer several options to which student can agree (yes) or disagree (no).</td>
<td>Use word banks, fill in the blank formats, familiar templates.</td>
<td>Let student present some information they have learned to other students.</td>
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<tr>
<td></td>
<td>Use of assistive technology.</td>
<td>Have students work in pairs and use other interactive strategies to teach and plan for meeting.</td>
<td>Provide templates and guides for planning for meeting.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide templates and guides for planning for meeting.</td>
<td></td>
</tr>
<tr>
<td>Preparing for meeting participation</td>
<td>Together with the student create a PowerPoint / Prezi presentation they will use to share information at meeting.</td>
<td>Help the student create PowerPoint / Prezi presentation they will use to share information at meeting.</td>
<td>Guide and support the student to create PowerPoint / Prezi presentation they will use to share information at meeting.</td>
</tr>
<tr>
<td></td>
<td>The student can select photos and videos to include.</td>
<td>Use graphic organizers, file cards and other materials to support student’s presentation.</td>
<td>Pair students together to practice. Allow a student who has already participated successfully in the process mentor a student learning the process.</td>
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<tr>
<td></td>
<td>Provide multiple opportunities for practice.</td>
<td>Practice before meeting.</td>
<td></td>
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<tr>
<td></td>
<td>Pair the student with a mentor student who has already directed their IEP.</td>
<td>Pair the student with a mentor student who has already led their IEP.</td>
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</tbody>
</table>
**Sharing assessment information:**
It is important during the assessment and preparation phase that the student, to the greatest extent possible, understands 1) the tools used to gather information about the student’s strengths, learning styles, annual progress and support needs; and 2) the results of the assessments that are conducted and how the information can be used to identify meaningful goals for the next year as well as appropriate services and supports. It may not be possible for all students to understand the assessment tools and results in any meaningful way, especially if there is an intellectual impairment involved. In such cases I personally believe the educators should expand their assessment to include more authentic, ecological-based assessments that actually highlight what the student can and likes to do; identifies the student’s skills, strengths and interests in familiar contexts and activities; and describes that supports and accommodations are useful and helpful and those that are not. With this type of assessment approach it will be easier to involve a student in recognition of the assessment process on some level.

The student should also be provided the opportunity to share what they recognize as their achievements and progress over the past year, areas that need more work or attention, and supports and accommodations that are helpful to them. A student can be guided and encouraged to evaluate the progress they have made in the past year by reviewing sample of class work and projects, completed data sheets and other simple progress checklists, curriculum assessments (e.g. vocabulary lists, reading scores, math skill standards achieved), and any performance evaluations offered by employers or job coaches. For some students it will be necessary to adapt how the assessment is presented. Visual or tactile graphs indicating amount of growth or progress, or a visual or tactile example of increase in number of times a skill was performed or number of new tasks or activities learned and completed might be very helpful.

**Identifying, selecting and drafting goals:**
A wonderful outcome of the student-directed IEP process is the central focus of the discussion on the individual student’s strengths, areas for growth, goals, and supports and accommodations needs. Potential goals should be shared with the student before the meeting. For some students they will lead this discussion of potential goals, for others they made need to be provided with choices, and for still others they may need to be offered the opportunity to agree or disagree with the suggested goals.

I notice that the students are more engaged when reflecting or self-recording IEP goal data. They simply understand that they have goals that they are expected to work on. It’s also great if they can help create their goals. Last year I taught a student who LOVED Google maps so he had a goal that was about planning community outings and bus routes in which he was able to use Google maps. This year one of my students identified that he wanted to work on writing because he really likes to read in English class, so we sat down with his English teacher and came up with a narrative writing goal using cloze reading methods [a strategy in which the reader is asked to supply words that have been systematically deleted from a text to demonstrate comprehension]. I think that involving students motivates them to take initiative rather than be a bystander when it comes to their IEP goals. I also think that giving the students a little bit of power goes a long way and makes what can be a mysterious IEP process a meaningful process.

~ Dana Zimpelmann, high school inclusion support teacher
Some of the following strategies might help with selecting goals to present to the team:

1. Discuss with the student what they learned from the assessment process. Together identify areas where skills are needed or could be improved or identify specific activities or tasks that the student would like to learn.

2. Review last year’s goals and ask these questions: Have I met that goal? Is this goal still important to my life? Is it a good goal but it needs some changes or more accommodations?

3. Offer the students suggestions or choices of goals that are based on their interests, current skills, future goals, or activities and skills other same-age students are learning and practicing.

4. Consider all relevant areas for goals: academics, social, communication, vocational, independent life skills, self-determination and self-advocacy, leisure and recreation. Select goal(s) for each area.

5. Design a guide that the student can use to ask other people who are important in their life for ideas about potential goals (e.g. parents, siblings, extended family, friends, support staff, general education teachers, counselors). Students in a transition program in San Francisco provide people in their close support circle a guide to provide written feedback on the student’s strengths, areas of need, potential supports, ideas for goals, and hopes for their future. The students then incorporate this information into the PowerPoint presentation they use at their meeting. The guide included these questions:
   - What do you think I am good at? (strengths)
   - What strategies help me do my best? (services, supports, and accommodations)
   - What kinds of situations don’t work for me? (services, supports, and accommodations)
   - What do I need to work on to be successful and achieve my future goals? (areas of need)
   - What are your hopes for my future?

Students will need assistance and support to write draft goals to present to their team. It helps to use a specific format to plan potential goals with a student, such as:

“In one year, (list any accommodations or supports that will be used and context) I will _____ (list measurable behavior) _____ (list criterion for measurement such as accuracy % or number of times).”

The educators and parents can then refine the goal with any additional language that is necessary for IEP, but the goal itself should be understandable to the student. Such as:

“At my job sites, I will greet my coworkers with handshakes or high fives rather than hugs.”

“I will use my BrailleNote and personal FM speakers to listen and take notes during presentations and small group work in each of my classes.

“I will use my picture boards to express my wants and needs to my teachers, classmates, and family.”

The actual IEP goals and objectives included in the final IEP will have more specific language included related to conditions, context and criterion for measurement of the goal and accompanying objectives. For most students the essential information they need is the expected behavior(s) or skills and any necessary accommodations or adaptations to meet the annual goal.
Participating at the meeting

In traditional IEP meetings the student typically holds small and a passive role that usually involves listening and offering agreement for others’ findings and suggestions. However, there are many meaningful ways a student can actively participate and contribute at the IEP meeting. For one student it might include welcoming everyone to meeting, passing out snacks and stating agreement or disagreement to information and goals prepared before meeting and others’ feedback and ideas. For another student it might include welcoming and introducing everyone, presenting examples of classwork and projects, and sharing a poster collage or PowerPoint presentation of their year in review and a list of goals for the next year. Yet another student, may follow a script to introduce each part of the meeting, present assessment information they gathered in a variety of formats, use PowerPoint to present a summary of their strengths, need areas, supports and accommodations, and suggested draft goals, and actively seek feedback from other team members.

If you are not sure what a student-led PowerPoint presentation might look like I have included a template some students have used to create a PowerPoint presentation for their team meeting on the final page of this article.

Supporting the student’s involvement and success: When you first begin to support students to take a more active lead at their IEP meeting you will need to consider and provide the supports and accommodations the student will need to be comfortable and successful. Remember this is an exercise to promote self-determination, self-awareness, and self-advocacy and these are skills that evolve and improve with more practice and experience. Some students may be nervous directing the meeting or presenting in front of others. Others may have difficulty acknowledging or accepting feedback from other team members. Other students may need specific tools to successfully lead and/or participate in the meeting’s discussion. Tools might include use of a PowerPoint or Prezi presentation, index cards with notes, switches to control presentation or use a speech generating device, color-coded cards that alert you that a student needs help or a break. You and the student will want to come up with a plan before the meeting for how you and other team members can support the student’s participation at the meeting.

Providing support at the meeting

A young man in transition program shared, “I am not sure I like to lead my IEP because it makes me nervous to talk about me in front of everyone. I don’t think every student should lead their IEP, the student should be asked if they want to do it or not. But, I really like that part of getting all the information together for my IEP. I like that the teacher meets with me and asks me what do I think about my goals. All my previous IEPs (before Access) no one asked me what I thought. I felt my teachers and parents didn’t care what I thought. But now I can tell them what I like to do or not.”

Edith Arias, a paraeducator’s impression of this statement: “This is his second year in the school. He is one of the most articulate students in the school and can really express his frustration and is working on self-regulation as one of his goals. I see him as very aware that managing his frustrations is important to him because he helps plan his IEP. I didn’t know that he didn’t like to lead his IEP, so this is a new idea for me! Maybe not everyone should lead it if it gets to be too uncomfortable.”
<table>
<thead>
<tr>
<th>Support Needs</th>
<th>Participation Suggestions</th>
</tr>
</thead>
</table>
| Students with minimal support needs | • Use PowerPoint or Prezi to present.  
• Provide name cards in front of each person.  
• Develop a clear step-by-step agenda with highlighted information for student to refer to during meeting.  
• Have note cards with information prepared and ready.  
• Have a system the student can use to ask for assistance or to pass on duties if necessary (e.g., color coded cards, a signed gesture).  
• Model respectful interactions with student that demonstrate understanding of the student’s role as the leader of the meeting.                                                                                                                                                                                                 |
| Student with moderate support needs | • Use a PowerPoint or Prezi to present and include simple text student can read and photos and video clips.  
• Pre-record audio comments or video to include in presentation if necessary, especially if student will be too nervous to present.  
• Follow a predictable format throughout discussion.  
• Follow a pre-planned agenda in which the student leads portions of the meeting and the teacher or another facilitator leads or co-leads other parts with input from student.  
• Use graphic organized or note cards with steps to follow.  
• Use guiding questions to prompt student to perform their planned roles and tasks.  
• Restate student’s statements or requests when necessary.  
• Model respectful interactions with student that demonstrate understanding of the student’s role as the leader of the meeting. Have a system the student can use to ask for assistance or to pass on duties if necessary (e.g., color coded cards, a signed gesture).  
• Make sure student is seated next to someone who knows their support plan for the meeting.                                                                                                                                                                                                          |
| Student with higher support needs   | • Use assistive technology for the presentation: switches, prerecorded messages, signed communication, speech-generating devices.  
• If student uses a speech-generating device you can record it ahead of time and play the recording of the presentation at the meeting.  
• If the student uses signed communication or ASL an interpreter should be at the meeting to help student present.  
• Make sure student has a means to communicate during meeting presentation and discussion and ensure all team members acknowledge the student’s messages.  
• With a PowerPoint or Prezi presentation include text that team members can read and insert slides that elicit feedback from other team members.  
• Plan a specific amount of time for the student to present information they wish to share. This may occur at one specific portion of meeting or at numerous planned times throughout the meeting.  
• Provide the student with fidgets, breaks, etc. throughout the meeting.                                                                                                                                                                                                                           |
Implementing and evaluating progress on goals

This is another important phase in which the student needs to be actively involved. Once a student has prepared for and then led and/or participated in the planning of new goals at their meeting, they need to be involved in implementation and evaluation of their goals. The student worked hard with others to create meaningful goals and a plan for the year and now it is time to pay attention to supporting the student’s understanding of this phase. The student needs to recognize that once the goals have been set, they need to consistently work toward attaining the goals and evaluating progress toward that goal attainment.

It is critical that the student understands the expectation of each goal and how it will be measured. As discussed earlier it is important that IEP goals are specific and clear and measurable. Students need to easily understand the goal in order to be able to evaluate their progress. Some examples might include:

- I will ask at least one friend to join me in card game and take turns in the game at recess 3 times a week.
- I will plan my routes to community work sites using Google Maps by entering the departure and arrival points and time of trip, printing directions, and following the listed directions and times.
- I will meet with my teachers each week to review the class materials that will need enlarged print copies for the following week.

The goals the team and student develop should also be goals that can be met in reasonable time frame and can be practiced on regularly basis (e.g. daily or weekly). For instance rather than setting the goal “I will graduate from high school”, set a manageable goal that will help the student achieve that future outcome, such as “I will contribute at least one comment or question in all class or group discussions, complete my daily homework and class projects, and meet with my support teacher and school counselor once a month to review my grades in each class.” Rather than a broad goal with no measurable behaviors such as, “I will do a good job with my coffee cart position”, write a goal that states exactly what is expected, “Every Tuesday and Thursday morning I will complete an inventory of coffee cart supplies, greet customers, take their order, and provide them with the items they requested and the correct change for their purchase.”

Several secondary and transition teachers have shared with me examples of creative data sheets which their students use to chart their own performance and progress on specific goals on a regular basis. I think this is a great practice as it helps make the connection between assessment and IEP goal development. It also gives the students practice with setting goals, whether educational or personal goals, and then regularly assessing progress or benchmarks toward meeting those goals. I have included a few samples of these types of data sheets below.

---

**SELF-ASSESSMENT OF GOALS**

I would suggest giving the student an individualized tool and working goal progress recording or self-reflection into the student’s daily schedule. Last year, my students did it every day during 7th period. They used the same tool at the same time each day and eventually almost all of them completed it independently, and brought it to me asking for my input. This process became a part of the students’ day that they could count on, recording their progress was motivating, and they became extremely independent. ~ Dana Zimpelmann,
The data sheets could be simplified to include a thumbs and thumbs down icon or other picture symbols or photos. They could also be adapted to include Braille, or used with other assistive devices such as iPad, computer, AAC device. A student could also simply tell or sign to a support person what to record for a response when completing a self-assessment of their work and progress on a goal. Some sample data collection used by high school and transition aged students are included below.

### IEP Tracking

**Writing Emails** – complete 2-3 times a week with staff

<table>
<thead>
<tr>
<th>Day</th>
<th>Did I use my checklist?</th>
<th>Who did I email?</th>
<th>Did I have correct email format?</th>
<th>Did I have correct capitalization?</th>
<th>Did I have correct punctuation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wed 9am</td>
<td>Yes</td>
<td>No</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
</tr>
<tr>
<td>Thrus 9am</td>
<td>Yes</td>
<td>No</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
<td>With a lot of help</td>
</tr>
<tr>
<td>Total</td>
<td>/ / Yes</td>
<td>xxxxxxx</td>
<td>xxxxxxx</td>
<td>xxxxxxx</td>
<td>xxxxxxx</td>
</tr>
</tbody>
</table>

**Job leadership** – Complete after Coffee Cart

<table>
<thead>
<tr>
<th>Day</th>
<th>Did I start my task right away?</th>
<th>Did I help ______ or ______ when they needed it?</th>
<th>Did I communicate with my job supervisor?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tues</td>
<td>With a few reminders</td>
<td>With a few reminders</td>
<td>With a few reminders</td>
</tr>
<tr>
<td>Fri</td>
<td>With a few reminders</td>
<td>With a few reminders</td>
<td>With a few reminders</td>
</tr>
<tr>
<td>Total</td>
<td>/ / a few reminders</td>
<td>/ / a few reminders</td>
<td>/ / a few reminders</td>
</tr>
</tbody>
</table>

Turn Over ---->
### and make topics and visuals in each

<table>
<thead>
<tr>
<th>Date</th>
<th>Main Idea</th>
<th>Detail</th>
<th>Class Subject</th>
<th>Confidence Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td></td>
<td>Got It / Kinda Got It / Need to Review</td>
<td></td>
</tr>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td></td>
<td>Got It / Kinda Got It / Need to Review</td>
<td></td>
</tr>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td></td>
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<tr>
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<td></td>
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<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td></td>
<td>Got It / Kinda Got It / Need to Review</td>
<td></td>
</tr>
</tbody>
</table>

### Write a 5 paragraph essay:

<table>
<thead>
<tr>
<th>Date</th>
<th>Main Idea</th>
<th>3 Body Paragraphs</th>
<th>Conclusion</th>
<th>Effort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>A  B  C  D  F</td>
<td></td>
</tr>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>A  B  C  D  F</td>
<td></td>
</tr>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>A  B  C  D  F</td>
<td></td>
</tr>
<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>A  B  C  D  F</td>
<td></td>
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<tr>
<td>Yes / No</td>
<td>Yes / No</td>
<td>Yes / No</td>
<td>A  B  C  D  F</td>
<td></td>
</tr>
</tbody>
</table>

### Keep things organized:

<table>
<thead>
<tr>
<th>Date</th>
<th>Turn in Work</th>
<th>Put work in binder</th>
<th>Composition book</th>
<th>Used echo pen</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

### Tells friend or teacher how to make correct geometric constructions:

<table>
<thead>
<tr>
<th>Date</th>
<th>What did the drawing look like</th>
<th>Did helper understand your directions?</th>
<th>Did you get the problem correct?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Yes / No</td>
<td>Yes / No</td>
</tr>
</tbody>
</table>

### Work Habits

<table>
<thead>
<tr>
<th></th>
<th>Try Again (told) (1)</th>
<th>O.K. (ask/hint) (2)</th>
<th>Awesome! (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I got to work on time; I was ready to leave the class when I needed to be</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I put my stuff away, used the br, was ready for work when shift started</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I said hello/gbye to my supervisor and coworkers; engaged in short conversation w/customers, sup., coworkers as appropriate.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I asked for help if I didn't understand what to do.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kept talking to friends and goofing around to a minimum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I focussed on the job I was given until it was all done.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I gave it my best effort and did the best job I could do!</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I asked for a break if I felt I needed one.</td>
<td></td>
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</tr>
</tbody>
</table>

**Total Score:**

### MUNI (average both trips)

<table>
<thead>
<tr>
<th></th>
<th>Try Again (told) (1)</th>
<th>O.K. (ask/hint) (2)</th>
<th>Awesome! (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stayed awake and aware for the duration of trips</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knew which route to use/bus stop to walk to</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulled chord before the stop</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I knew where to go, so I looked out for and helped the other CAT students</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gathered belongings and exited the bus quickly</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total Score:**
I hope you and your students find the strategies and tips I’ve included in this article helpful. I would be very happy to hear your thoughts about the student-directed IEP process or answer any additional questions about using this approach in the comments section of our newsletter page. If you have any tips, strategies or success stories you’d like to share with others, please feel to share in the same comments section. For more information about additional available resources please see the final page of the original article “It’s my life: Considering the student-directed IEP process” at http://www.cadbs.org/newsletter/resources-summer-20152/.

Author’s note: I wish to offer special thanks to Edith Arias, Alyson Furnback, Heidi Seretan, Dana Zimpelmann, Jennifer Kabbabe, and Elise Schaeffer for sharing so many practical ideas, examples and personal reflections related to the student-directed IEP approach with me. These incredible and dedicated educators are all graduates of the SFSU Moderate-Severe Disabilities Program and we are very fortunate for their continued work in our local public schools.

Recommended Resources:


I’m Determined Project —Wonderful Internet resource for educators, families and youth on a variety of topics related to self-determination and self-advocacy. This project was developed by the Virginia Department of Education. It includes a variety of resources that teachers can use to organize student involvement in their IEP meetings, including lesson plans, templates, self-assessments, checklists, brochures, and PowerPoint Training slides. [http://www.imdetermined.org/]

IEP Involvement Tool from I’m Determined Project: Helpful tool for teaching and preparing students for the IEP process. [http://www.imdetermined.org/resources/detail/02_iep_involvement_tool]

My Future My Plan.

This curriculum is designed to motivate and guide students with disabilities and their families as they begin early transition planning for life after high school. The curriculum package includes a videotape and discussion guide, a workbook for students, and a guide for family members and teachers. All materials are available in English and Spanish. [http://www.ncset.org/publications/mfmp.asp]

FYI Transition Self-determination Resources: This website includes a comprehensive list of many curriculum available to teach self-determination, self-advocacy, goal-setting, and IEP participation. The list includes a detailed description and contact list for finding or purchasing the curriculum: [http://www.fyitransition.com/ Minicourses/selfdetermination/selfdetermination6.html]