



# Fact Sheet

## Self-Determination Is For Babies, Too!

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In the field of deaf-blind education there are many classic strategies that must be adapted and individualized to fit the needs and preferences of each student. Overriding all of these are a small number of philosophical concepts that are so important and universal that they are best stated as imperatives – among the most important are **“Know the child!”**, **“Follow the child!”**, **“Individualize!”**, and **“Do with, not for!”** All of these ideas, if respected and used properly, should ultimately help the child to acquire a strong sense of self-determination and independence.

But there seems to be widespread misunderstanding about what the particular phrase “self-determination” means, especially when it is applied to the population of children with deaf-blindness. In my experience, most people tend to think that it means transition to adult services and the kinds of things that we need to do with the student when they’re in their mid to late teens, but that view is actually very narrow and exclusive and really misses the point. Self-determination is something that we should begin thinking about and facilitating the day that the child is born. It’s something you do with young babies, and with toddlers, and with children all through school-age, and with adults in just the same kind of way. Of course you adapt to make things age-appropriate, you adapt for individualized needs, but self-determination should always be right at the front of the agenda, in everyone’s mind, all the way through. This is *not* about teenagers and leaving the school system, this is about human beings growing and adapting and learning, and feeling confident that they have some predictable control over their lives.

Following from that popular misunderstanding, people also often assume that self-determination means things like finding some kind of job, some kind of paid employment, that it means acquiring your own home on some level, learning to use public transportation, and those kinds of issues. And again, I would say that’s only a very limited and limiting view. It really has to do with the individual’s self-image more than anything else. All those things I’ve just mentioned may be important at some point in time, but to me they would never be the prime focus of any kind of work on self-determination.

I think all of this should all come from within that individual person: How do they see themselves? Do they have a good self-image? Do they have the confidence to express themselves in a way that is likely to get them what they need and what they want? Do they feel that they can relate to other people in a positive way without being either fearful or overly assertive or aggressive? Do they know that they can reliably do certain things for themselves, with predictable results? Or, are they people who’ve given up

and are really so sunk in despondency that they just don't try any longer to communicate? Trying to keep thinking in terms of self-image is very important, particularly at that early intervention stage. People rarely think of babies having a self-image, but I believe that all babies are aware of failure, they're all aware of negative responses from the world around them, and they all respond well to success—however disabled or non-disabled they are.

### **So much depends on us**

Progress towards self-determination is very dependent on the behavior of the most important persons around the individual. The child's own self-image is going to depend upon other people's image of them. All children need to grow up with people who are observant and responsive and respectful of THEM—who they are, how they are, what they're interested in, what they like, what they want and what they don't want, and how they express themselves. These important people need to convey to the child their belief and expectation that the child can become competent in many ways and in many areas, which means that they need to get the right balance between protection and independence. The child should be encouraged and allowed to do what they are capable of doing without other people providing too much help. This has to be a primary aim in any kind of interaction and intervention.

I'm a teacher, so my special interest is education, and it can be difficult when people try to bring an educational plan in from the outside, as it were. They then try to make the child fit in with it rather than starting with the child and saying, "Who is this person?", "What does he or she like?", "What are they into?", "What do they do?", and "How can I introduce myself and build a relationship so that they may want to do things with me?" If all of these things are done first then we can start more of our active intervention and teaching by asking questions like "What do they need to learn?", and "How can we help them to get there?" and "How can we help them to become more completely and fully who they are?"

### **What is the child telling us?**

It's important to think about the way a child is being understood by their family and the way that the family is interpreting the child's behaviors. Experience shows that it's an area that often gets neglected by professional support agencies. Because the children tend to have such complex needs and a wide range of developmental issues, especially in the area of communication, where they may appear unresponsive or idiosyncratic, adults are not really thinking in terms like, "Ah yes, this child has a consistent way of expressing a whole range of needs, and emotional states, and interests."

Sometimes it helps just to ask a family to think about that area, to prompt them a little. And I often pick up on the fact that during my visit a parent may have told me that their child is a little anxious this morning, or that their child really likes something, or that the child is getting hungry and wants her lunch. Then I ask the parents "'how do you know those things; what did your child do or not do that told you what was going on inside their own mind?" And parents often look rather confused and surprised because they almost didn't even know that they were being told all of these things by their child.

It's really a case of bringing up all that instinctive understanding that's been built up ever since the child was born, fetching it into the conscious mind, and then verbalizing it, so that we realize just how much there is there to work on and how much might be being responded to appropriately on an unconscious level. But if this information is acknowledged on a conscious level, we've got a lot more room to develop, foster and encourage it. Also, if it comes onto that conscious level, a parent can start telling other people about it and sharing their insights with the wider world around the child. And that's a huge part of beginning the path toward self-determination for the child. People tend to have the lowest expectations of the children with whom we work, and they think in terms of the most basic kind of measurable, concrete skills (such as can the child reach for something and grasp it, can they eye-point to

it, can they feed themselves with a spoon, how many words or signs do they use) but there's far more involved than that. And the child's emotional heart—their needs, wants, interests, hopes and anxieties, their feelings about themselves—is really where our work should be focused. Here are a few topics that are helpful to consider:

### **1. The “Just Right Challenge”**

One important concept is that of the “**just right challenge**,” the idea that the child should be helped and supported up to the point that they can be left to deal with the challenge and do something for themselves with a fair degree of guaranteed success. The essential learning or teaching point is reached when the child is no longer having to do something well-within their competence that needs no active thought (almost like driving on auto-pilot) but is instead having to rise to the challenge of experimenting, or using trial and error, or asking someone for help. In this way we avoid making the child the passive recipient of whatever happens to them, minimize the risk of boredom (for both the child and ourselves), and generally keep life interesting with just the correct amount of ‘good stress’. Getting this right demands that we have a good up-to-date knowledge of the child, their interests and previous experiences, their expressive communicative behaviors, and their current skill levels. Knowing the student is the very first requirement for anybody who is going to be involved in interactions with them.

### **2. Consistent Routines**

For most children in this population it is helpful to establish a pattern of consistent routines both big and small—from the precise way that socks and shoes are put on and taken off to the way that the entire day, or even the entire week, is structured. But these consistent routines are used to help the child understand what is going on, and to anticipate what is coming next, and so feel more comfortable and confident. They are not intended to remove any need to think or to problem solve, but they provide the scaffolding that supports the child and gives them the confidence to try new things and so learn new skills. A good general rule is to look for indications that the child has recognized and remembered and anticipated a familiar routine, and then change it in some way. This could involve extending the routine by adding more to it, so the child has to extend their attention and knowledge. Or it might mean altering the expected pattern of the routine (in other words, abandoning the consistency of it in some small way) so that the child has to pay attention, work out what is different, and then put things right again or ask somebody for help in putting it right. If the challenge that these changes presents is indeed “just right” then the child will cope and respond with interest and curiosity without getting unduly stressed or upset or just giving up.

### **3. Constant & On-going Observation**

Only close, meticulous, and on-going observation will allow us to know what the “just right challenge” is, from moment to moment and from activity to activity. Hence the need to be available and informed and involved even if not actively intervening in what the child is doing. Ernest Hemingway famously told us not to mistake movement for action, and anyone who has spent time in genuine careful observation of a child who is doing things for themselves will know that it can be very much more challenging and exhausting than simply doing everything for the child through the day, but it is an essential component in any successful teaching plan. For all of us, a feeling of independence and control is essential for the development of a good, positive self-image, and this goal should be present in the minds of everyone working with each individual child.

### **4. Interactions as Conversations**

Another important concept in this field is the idea that every interaction with the child should be regarded as a conversation. With their vision and hearing missing or limited, the child's processing time and preferred pacing will very often be different from ours. The only way you can "Do with, not for," is if you pace your interactions with the child in such a way that they can attend to and understand, which might mean going slower or faster than your normal interactive pace. Of course, as in any conversation you also need to pause so you can give time to the child to respond, remembering that the type of response will vary depending on the way that the child expresses themselves. These responses may be very subtle and idiosyncratic, another reason why it is so important to be a good observer. Another thing to remember is the importance of providing appropriate opportunities for the child to make informed choices. These choice-making experiences, and the natural consequences that inevitably result from the choices made, are fundamentally important to the development of self-determination and independence.

## **5. Reactive & Accessible Environments**

In promoting her Active Learning approach, Lilli Nielsen often talked about the dangers of "learned helplessness"—the inevitable outcome for a child who has always had everything done for them but has never been allowed to do anything for themselves. A major component of Nielsen's approach is the creation of child-sized and child-accessible environments which the child can manage by themselves. The adult's role is to get the environment right so that the child is motivated to interact with it and facilitated in doing so. The adult is expected to be ready to intervene to facilitate and extend what the child is doing when appropriate, but their main role is to observe as the child does things all by themselves. In many different ways, and throughout the age range, adaptations to the environment can play a significant part in teaching and in promoting confidence and independence.

## **6. Personal Passport**

Creating an individualized Personal Passport for a child is another idea that can help enormously with this process. Working on making a passport can help a family to realize and recognize and actually write down their understanding of their child. It can help them to answer questions such as what the child likes and how we know they like it, what the child wants and how we know they want it, what they don't want and how we know they don't want it. And then putting this information down in written form and putting it in a Personal Passport means personalizing it with the child's name, with lots of photographs, maybe writing it in the first person, and updating it regularly so that the book will truly reflect who they are. And in theory, once it is done, any stranger who comes into the child's life who has access to the Personal Passport should be able to start off in the right way. Also, it helps all of us to remember that this is a child who is a complete human being with likes and dislikes and memory, and a history of expressing themselves in ways that can be understood by the people around them—the first stage of any kind of progress towards self-determination.

### **Parent/professional collaboration around self-determination**

From my perspective, the first step in promoting self-determination for a child is promoting self-determination for the family. Building good parent-professional collaboration is a bit like dancing, about finding the right partner, which is so important. In my experience, many parents have come across professionals who are not actually very collaborative, who tend to come into the relationship with very stereotyped views or perhaps with a very directive approach. This may suit some parents, but doesn't suit everyone.

This collaboration involves the coming together of two valuable resources: first, that in-depth, individualized insight that the parent has had to develop of necessity by living with the child from birth,

and second, the breadth of the professional's training and experience across the field, even though they may initially have little knowledge of that particular child. Finding ways to bring these two things together depends on the professional in the duo being open to and valuing and respecting the depth of the parent's knowledge of their own child.

We pay a lot of lip service these days to the idea that the parent is the greatest expert of their child. I think that idea may sometimes be experienced by parents as a burden; it can be a way that some professionals who feel out of their depth avoid getting too involved. But there's a way of saying very respectfully, "I need your knowledge of your child. I bring a lot of expertise that could be very relevant and I'll try and share it with you, but we'll have to work on it together to make it relevant for your child. And maybe I can help you realize just how much you know, because there may be things of enormous importance that you've never realized have that kind of value. And we can go along that road together."

Teachers can't do everything alone but neither can parents. It is the truly collaborative relationship that adds up to much more than the sum of its parts. As the number of people involved in the professional team increases, everyone should understand that no one on the team is more important than anyone else, and that over time each person's "special interest" is likely to become more or less of an urgent priority depending on many factors. For all of us, not only for children with deaf-blindness, good self-determination will include knowing when to be quiet and listen, when to speak up, when to allow somebody else to make decisions, and when to take action ourselves. And that's always seemed the most effective way, I think, to build those collaborations. It's a challenge that has absorbed me for over 34 years now, and I love helping parents stand back and really look at the breadth and depth of their knowledge of their own child. To me, it's the starting point in getting the child perceived as a person who needs to have control over their life in appropriate ways.

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