

THE MEANING AND PRACTICE OF ACCEPTANCE

LONG-TERM AND SHORT-TERM GOALS FOR AUTISTIC CHILDREN

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Introduction: Identity, values and meanings

A good life is not necessarily an easy one. Many persons compromise their convenience, property, or even health or safety, to pursue whatever is important for them. On the other hand, the worth of disabled people's lives is sometimes questioned even in cases where the person is well cared for and doesn't have to do anything for themselves. Moreover, loss of control over one's life is often accepted as an argument against the validity of a life with a disability, because without autonomy, a person cannot seek out what is meaningful for them.

At the core of education, the issue of meaning – of what is important in life beyond physical existence – concerns parents, teachers and other educators and caregivers. Meanings and values are relevant to every conscious being throughout all stages of life, because they affect our daily thoughts, feelings and choices, whether we are aware of it or not. A value is something we want to maintain for its own merit, not as a means for something else. In the individual context, values may be virtues like integrity or diligence, or development of talents like art and music, or lifelong goals like religious worship and participating in one's culture. In the interpersonal context, values may be establishing and caring for a family, having good friends, or involvement in one's community. In the realm of society, values may be the fight for justice and equality, or serving one's country.

Choice and priorities of values vary among societies and among individuals within a society. Choosing and maintaining values requires self-awareness and autonomy, which are components of, or conditions for, an identity. A strong sense of identity, which is the cornerstone of a meaningful life, is developed both from self-awareness and from a sense of belonging within a community and a culture.

In order to pursue one's values, one needs a certain degree of independence, which may be considered a value itself. Independence is a result of acquiring various skills, e.g., self-care skills for daily life independence or vocational skills for financial independence. An important skill is the ability to make informed decisions, based on personal values and on a realistic assessment of the situation.

A sense of identity, meaningful connections, and independence are important components of quality of life. The need for a good life, beyond the basic needs, is demonstrated by Maslow's Hierarchy of Needs. Abraham Maslow defined a hierarchy of need-categories: physiological, safety, love, esteem, and self-actualization. Once the needs in one category are satisfied, the individual is motivated to satisfy the needs in the next higher category. The highest category, the need for self-actualization is *the desire to become more and more what one is, to become everything that one is capable of becoming*. Although Maslow's categories are questionable,

his ideas are widely mentioned in context of quality of life, to illustrate the desire of human beings to grow and to seek for meanings beyond physical existence.

Long-term goals for children

Education aims to enable self-fulfillment and achievement of long-term goals by providing the child with a toolbox and a treasure-chest. We should teach our children not only practical skills (i.e., tools) for gaining independence, but endow them with “treasures”: our meaningful relationships, values, and culture. The latter, being personal choices, can later be maintained or discarded by the young adult emerging from the process, but choice is meaningful only if one knows the possibilities. Moreover, even if the person ultimately decides to seek for totally different relationships, culture, or values, he or she will still have gained the important concepts: The concept of relationships, the concept of being part of a culture, the concept of maintaining values.

The meaning and importance of acceptance

It is easy to see, why acceptance is important for maximizing the child's potential. Acceptance means to recognize the essence of the person, and to respond accordingly. Potential is usually associated with talents, and acceptance means to recognize, among other things, the unique talents of the child and to help him or her develop them. Acceptance also promotes efficient learning by recognizing the unique learning style of the person and adapting teaching methods accordingly.

But the importance of acceptance goes beyond talents and skills. In order to be motivated to satisfy higher need-categories, the child must experience a basic feeling of safety. Acceptance gives the child a feeling of having a place in the world, and the freedom to go where his or her mind takes them, and even to make his or her own mistakes. On the other hand, sending the child the message (either explicitly or implicitly) that he or she is inherently bad and should dump an important part of their core in order to become worthy, results in fear, self-hatred, and lack of self-confidence. Such a child will remain busy trying to satisfy the need for safety and will not be ready to pursue higher needs.

Responding according to the child's uniqueness may enhance his or her sense of identity by reflecting the child's specific characteristics and by differentiating between the child and other people (including the accepting caregiver). Without acceptance, mirroring and differentiation will have the opposite effects of confusion and alienation. Acceptance is also the basis for developing a meaningful relationship. If we want the child to experience reciprocity and sharing, we must be ready to accept the child before we ask the child to accept us; and we must share what is meaningful to the child before we ask the child to share our meanings.

Identity versus change

A wish to maximize the child's potential does not contradict acceptance, although it does imply changing the child's functioning. Potential is something that exists but is not materialized yet. Therefore, moving from potential to its realization means a change by learning new skills and new meanings, while preserving the essence of identity. For example, the essence of birds is flying; therefore a newly hatched bird has the potential ability to fly. Looking at the helpless chick and concluding that it is useless to teach it to fly is not

acceptance, although this conclusion is based on the current characteristics of the chick. Genuine acceptance should realize the potential of the chick, assuming the possibility of growth and learning. On the other hand, some species of birds lack the ability to fly, although they have feathers and wings. It is therefore important to know which species the chick is, something that is hard to do with young birds that do not resemble their adult peers.

The same reasoning applies to humans. Looking at the new-born baby, it is hard to imagine that this helpless creature will grow teeth, will learn to walk, talk, and read. However, these abilities are often assumed for a child who follows the normal developmental course, because normal people achieve these milestones. Harder to anticipate by observing normal development are the unique characteristics of each individual. Therefore, true acceptance should not only realize the present condition of the child, but carefully observe the emergence of his or her uniqueness. We must discover not only what the child can learn, but also what should be preserved and nurtured as the core around which the child's identity may take shape.

The essence of being human, according to Feuerstein, is the ability to change by setting goals and working towards them. Setting goals is an important skill not only for the caregiver, but also for the child. This skill requires higher cognitive functions, because goals are abstract – remote in time and place. Teaching children to set goals according to their own values will ensure preservation of their identity. Working with a child towards the child's own goals results in the most effective learning, because the meaning the goal already has for the child is a powerful internal reinforcement

Application to children with cognitive disabilities

When the child is disabled, all of the above widely-shared principles may seem to be irrelevant. To begin with, many people who do not have a first-hand experience with disability view a life with a disability as not worth living. Most people would not go to the extreme of advocating termination of a disabled life, but they would view disability as something to fight against and overcome.

Common caregivers' approaches to disability

The protective-passive approach assumes a set of skills that a person with a specific disability can or can't learn, and concludes that he or she will not grow up to be an independent adult. Therefore, treatment will aim to protect the physical and emotional well-being of the disabled child and to avoid conflicts related to the child's disability. Education, leisure, and, for adults, daily activities and housing are all planned in segregated settings, because functioning in the community is assumed to be too hard and stressful for the disabled person. Teaching will focus on the lower levels of the Maslow hierarchy: Daily life skills take precedence over more "abstract" goals such as academics and social or cultural values. It is assumed that cognitively-disabled children can not learn certain subjects, or that investing efforts in learning them would not benefit them in adulthood. When education extends beyond daily life skills, it is often limited to "leisure" activities like art, music and sports. Besides the "advantage" of not needing any academic background, these activities are often seen as a way of "brightening the lives of these poor children." Moreover, this approach often relates to disabled adults as if they were children, so characteristics of both activities and relationships with staff in adult programs resemble those of children's programs.

The dynamic-normalization approach, in contrast, highlights the ability of any human being to learn and adapt to a changing environment. It is based on a strong belief that disabled children can change, too, if given suitable guidance and support. Feuerstein's book, ***Don't Accept me as I am – Helping Retarded Performers Excel***, describes the theory and implementation of structural cognitive modifiability. The ultimate goal is to gain functioning as close to normal as possible. Teaching methods are adapted to the child's disability (to maximize learning efficiency), but long-term goals are similar to those for non-disabled children. Activities are planned in an environment as close to normal as possible, because a) the child is expected to live and function in a normal environment when he or she grows up, and b) a normal environment continually provides changes and challenges which encourage the child to learn and adapt.

Each of the above approaches has its drawbacks. While the protective approach limits the disabled person to options available in segregated programs, the dynamic approach sets normalcy as the only legitimate way of living. While the protective approach discards general education as irrelevant to the disabled child, the normalization approach denies access to the wealth of wisdom accumulated in the disability community. While the protective approach overlooks the potential for gaining more independence, the normalization approach ignores disability as an important component of identity. Common to both approaches is the assumption that cognitive disability contradicts independence and self-awareness and that therefore the disabled child should either be taught to become as normal as possible (the goal of the dynamic-normalization approach) or be prepared for a life controlled by others (what the protective-passive approach maintains). Both approaches envision a way of living when the child grows into an adult without taking into account the disabled person's perception.

The disability community's approach

Many of the misconceptions about disability, and about cognitive disabilities in particular, stem from the lack of input from disabled adults who are self-aware and speak up for themselves. Many self advocates claim disability as part of their identity. They resent being limited to segregated housing and workshops but, on the other hand, choose to tailor their life style to their own pattern of difficulties and preferences, rather than trying to function like non-disabled people. The extent of desired integration into the general society is not automatically assumed, but is a result of a balance between various personal goals and choices. Sinclair writes:

If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms.

According to this identity-goals approach, disabled children should learn about their disability and about the various alternatives to choose from. For a disabled child, to become more and more what one is – to become everything that one is capable of becoming – means that *everything* includes also *disabled*. Therefore, disabled children, like non-disabled children, should be taught to set personal goals for various time scales, but the nature of these goals should not necessarily be similar to that of non-disabled people.

A prerequisite for achieving personal goals is independence, and caregivers may find it hard to imagine this disabled child growing to be an independent adult. At this point, let us

examine the meaning of independence for a normal adult. A human adult living in any kind of society actually depends on other people in that society for products and services that the individual can not provide on his or her own. A member of a community is viewed as independent if he or she has the means to pay for these products or services and the skills required to be an informed consumer of them. If a disability prevents the person from benefiting from the services available to non-disabled people, then specialized services (special education, vocational rehabilitation, medical care) should be provided by the state. Likewise, if the person is unable to earn enough money to pay for essential needs, then social security payments should compensate for that. The meaning of independence for a disabled person is thus similar to its meaning for a non-disabled person: to identify suitable resources and to be an informed consumer. To do that as an adult, the disabled child must learn about his or her disability and about the specialized services available.

Learning about one's disability requires a high degree of self-awareness, and people with cognitive disabilities are often viewed as unable to develop this concept. However, self-awareness does not depend on IQ scores or on emotional stability. Even disabled adults who need a lot of help in daily life and in decision-making can have personal goals that are very important to them. Therefore, it is wrong to exclude them from learning "abstract" concepts simply because these concepts don't have immediate practical merit. A person may seem to lack self awareness because of not caring about social norms, or because he or she makes decisions much different than a normal person would. As with the issue of independence, self-awareness and values have the same degree of importance in the life of a cognitively-disabled person; they may just manifest differently, and acceptance means recognizing the individual's potential for independence and for self-awareness in spite of its non-standard manifestation.

Accepting a disabled child

Acceptance does not mean we make no demands of the individual. Believing in the ability of disabled children to learn and in their right to make their own decisions entails the responsibility to teach them the skills necessary for living in society, i.e., social skills. Children who learn to guide their own behavior have more options to enjoy societal resources and pursue personal goals.

Accepting a disabled child means not only recognizing the personal characteristics of the child, but also learning about the child's disability. Gaining insight into the nature of the disability and about services available to people with this disability is important for recognizing the child's potential and for developing long-term goals. This insight is best developed in the context of the community of adults sharing the specific disability. Learning about this community and its role in the lives of its members, reading their writings, and communicating with them can provide information not only about the practicalities of living with this disability, but also about the nature of their self-awareness and personal goals.

Finally, when setting long-term goals, one should bear in mind that learning is life-long. This is true for everyone, but it is especially important for cognitively-disabled people. The concern that disabled teens or young adults may not be prepared for adult life is often raised and used either to argue for vocational or life-skills training at the expense of general education, or to define the extent of independence the disabled person is capable of, based on

functioning level at a certain age. Because the development course of cognitively disabled people may be considerably different than the norm, important milestones should not be expected to happen at the same ages as in normal people. For example, if a 20-year-old man does not have the skills needed for handling his budget, one should not conclude that this man will always need financial supervision. If this man wants to have more independence in handling his budget, then caregivers should work with him towards this goal.

In conclusion, the presence of a disability should not influence the principles of child education, nor should it limit long-term goals to physical existence and to learning daily life skills. On the other hand, education should take disability into account not only for adapting teaching methods, but also as an important component of identity.

Long-term goals for autistic children

The common portrayal of autism is incompatible with identity, values and long-term goals. Autism is associated with severely impaired self-concept, often described in the framework of Theory of Mind. Autistic people are viewed as egocentric, thus uninterested in social or cultural values. They are not likely to develop meaningful relationships, due to communication and social difficulties. Finally, resistance to change – one of the hallmarks of autism – is a great obstacle to achieving or even setting long-term goals related to learning and personal growth. Those who succumb to this attitude would consider long term goals only inasmuch the child learns to function more normally.

If accepting an autistic child means learning about the nature of autism, then the first steps towards acceptance would be to throw away these misconceptions, to learn more about autism – mainly from within the autistic community – and to accept autism both as an important component of identity and as a specific way of experiencing and learning.

Acceptance is even more important in the case of autism, because the difference between autistics and NTs is profound in essential areas, not just in specific skills (as is the case with many other disabilities). To connect with an autistic child, the caregiver has to learn about autistic ways of relating and to employ them. The autistic tendency to focus on one channel at a time makes it very easy to lose contact with one's core: when forced to relate in normal ways, unnatural to the autistic child, attention is drawn to the outside world and the child may be unaware of internal processes. This does not mean that autistics lack self-awareness (as the Theory of Mind theory implies); it means that to help the child to develop identity and self-awareness, caregivers must let the child be his or her autistic self.

What – why – how

The purpose of education for autistic children is the same as for other children: to provide tools for achieving various values, so that they can choose what to keep when they grow up. When considering long-term goals, however, one should concentrate on the essence of each value, rather than on the way it is implemented for normal people. This way of thinking is important to avoid the immediate conclusion that any goal valid for a normal adult would be valid for a disabled adult only in so far as the latter can become more normal. As explained above, independence may take a different form in the life of a disabled person. A practical way to clarifying a goal is to ask why the child may want to achieve it when growing up. Once the goal is set, the means how to achieve it are usually tailored to the pattern of

strengths and difficulties of the specific child and are often influenced by the nature of autism. The rest of this section illustrates the development process for some common goals.

Normalcy

Raising a disabled child requires of the family a considerable amount of adaptation. Many parents mention long-term planning as their biggest concern. In case of an autistic child, the communication and interpersonal differences of the child may jeopardize the parents' ability to cater for the child's needs. It is therefore understandable, if the parents wish that their child were normal – especially parents of a newly diagnosed child. However, convenience is rarely brought up as a reason when examining normalcy as a long-term goal. Parents (of normal children) aspire for their children to follow their religious or cultural heritage, even when keeping these values may be dangerous. To find out why normalcy is desired, we must look for the values that might be lost through not being normal.

Normalcy is a value for many normal people, i.e., they want to be like everyone else for its own merit. However, most autistic people don't mind being different, and sometimes don't even notice it until their differences get them in trouble. Sinclair writes:

I just didn't start out with an expectation that I should be the same as other people... I've heard other autistic people say that they wish they weren't so different from other people for this reason: that they don't like being mistreated, and they know the reason for the mistreatment is that they're different and don't fit in... They want to be more like other people because of some perceived benefits that go with the status of fitting in, not because fitting in is especially desirable in itself. The idea of wanting to fit in for its own sake, of being different as a misfortune in and of itself, is not an idea I've heard expressed by autistic people.

Disabled people, like other minority groups, are at risk of discrimination. One of the meanings of being normal is having the same rights and choices as everyone else. Rights and choices are essential for achieving any personal goal.

Relationships are a common important value. Even for normal people, developing a relationship with someone from a similar background is much easier than with someone from a considerably different culture or life experience. A common belief – even among professionals – is that autistic children cannot develop a relationship unless they learn to communicate and relate like normal people. Even caregivers who respect autistic communication as a valid means of establishing a relationship may be concerned that the scarcity of autism might limit the opportunities of the autistic person to meet autistic peers.

Finally, normal people get to participate in the process of determining the norms. This is an important component of belonging to a community, which many people pursue as a value.

Now that the essence of normalcy is clearer, one can find out how to achieve it, without having to re-make the autistic child as normal. Education should prepare the child to live as a minority, in a society geared for others. From the justice aspect, education should include self-advocacy skills. From the relationship and community aspect, the child should have access to the autistic community and culture, as well as to autistic peers. Donna Williams writes that *normal is being among others like you*. Many autistic people who attend Autreat find the experience meaningful for their identity and for their sense of belonging within the

autistic community. On the other hand, segregated programs seldom provide this affirmation despite of putting autistic children together, as discussed below.

Social skills

Skills are utilitarian – not a goal in themselves, but tools for achieving values. Social skills are required for effectively interacting with others. Why is this important?

Social skills are often mentioned in the context of relationships, assuming that connecting with others is important for everyone. However, some autistic people may not view relationships as a value. Sinclair writes:

I'm not interested in relationships-in-general, or in people-as-groups. I can be very interested in individuals once I've met them, but I don't feel a need to have relationships in the absence of specific people to relate to... Mere proximity is no reason for me to become emotionally attached to anyone who isn't interesting to me as a person. Even when someone does attract my interest, when I do become emotionally attached and desire a relationship with that person, I don't become dependent on the relationship or on the person.

Social skills are required for using societal resources and for getting what one wants from others. A person who does not understand the rules of society or is unable to monitor his or her behavior needs constant supervision, thus has very limited control over xyr life.

Following the saying "when in Rome, behave like a Roman," we should teach our children the rules of Roman society, not how to become Roman. Living in society does not mean acting normal; it means behaving in ways that do not infringe on the rights of other members of society. Therefore, the child should learn the nature and the role of boundaries.

Understanding boundaries is also crucial for self-protection and has even more importance in the lives of disabled people, who are prone to being abused.

Relationships are meaningful only inasmuch they are voluntary. Therefore, the child should learn to distinguish between getting along with others and developing intimacy and mutual trust. An autistic child who is encouraged to interact with others only in normal ways might get a false concept of relationships and choose not to have a social life when growing up.

Communication

The ability to communicate – to exchange information and meanings – is an important social skill. Like other social skills, communication is used for both utilitarian purposes, e.g., to get something from others, and for voluntary purposes, like sharing and self-expression. The child should experience and internalize the meaning of communication before being taught the technicalities. Sinclair writes:

Learning how to talk follows from knowing why to talk--and until I learned that words have meanings, there was no reason to go to the trouble of learning to pronounce them as sounds. Speech therapy was just a lot of meaningless drills in repeating meaningless sounds for incomprehensible reasons. I had no idea that this could be a way to exchange meaning with other minds.

Normal people communicate mainly by speech, accompanied by intonation and body language. However, there are other ways to exchange meanings, and autistic children should

be provided with a variety of alternatives to normal communication modes, so that they can experience and find what works best for them. A variety of alternatives to speech are brought in Joel Smith's presentation in this conference.

A considerable part of NT communication is nonverbal. Nonverbal communication is so natural for NTs that they are seldom aware of its existence, yet they are influenced by its messages constantly. However, nonverbal communication does not work for autistic people. It may be useful for them to learn to identify and produce nonverbal signals consciously, to make communication with NTs more efficient, but their choice whether or not to employ these methods should be respected.

Working with autistic children towards long-term goals

Working towards long-term goals is done by breaking them up into short-term goals. In educational plans, short-term goals are often identified by picking typical autistic behaviors and aiming to extinguish them. Obviously, these priorities reflect a long-term goal of normalcy, that is not fostered in this article. This section describes how the long-term goals discussed above should influence decisions made in raising and caring for autistic children, as well as how the nature of autism should be considered to maximize efficiency of education and treatment.

Autism-related considerations in child upbringing

Development on various time-scales

Short-term goals should fit the developmental stage of the child. When planning for an autistic child, one should be aware that the pace of development may be slower than normal. Some children who are not interested in having friends become more aware of the social world and start to seek connections in adolescence or even early adulthood. Some areas develop faster than others, resulting in developmental gaps between various areas. As a result, the order of acquiring skills may be abnormal. Normal children learn to talk before learning to read. However, nonverbal children may learn to read earlier than normal and may never talk. Caregivers should be aware of emerging abilities and nurture them, while not insisting on goals for which the child is not ready, even if normal peers are expected to reach that stage at the child's age.

Pace of development may be uneven, consisting of "plateaus," where the child seems to be "stuck," and "leaps," where breakthroughs occur overnight. Rapid changes may be very difficult for the child, causing undesired reactions that may seem like "aggravation of autistic symptoms." Rapidly developing awareness may bombard the child with a flood of new information, requiring more processing time. Caregivers should consider this development pattern in order to understand that apparent lack of progress may indicate a period in which the child is processing and integrating previously acquired information and skills. At the same time, new undesired behaviors may be related to the stress of growth spurts. Assisting the child can be planned accordingly.

A similar pattern may appear on shorter time-scales. Autistic children may need longer times to integrate learned material, because making connections is not automatic. Sinclair writes:

Figuring things out and finding connections between different parts of a whole are what I do best, and I get a lot of practice because not many of the connections go into place by themselves.

Therefore, an interactive teaching method might not work for an autistic child, because the child may not be ready to demonstrate understanding during or immediately after a lesson. On the other hand, the absence of output from the child should not be viewed as if no learning is happening. Children with this learning style can be given exercises on previously taught material, together with passive repetition of newly taught material.

Another common pattern is fluctuation in the general functioning level or in specific abilities (e.g. speech). Gail writes:

There are times when I am more functional, and other times when I am less. Just the other day I got into it with hubby because he sees the times when I can do certain things. He then thinks I can do it all the time if I "try hard enough". That I am making excuses if I don't. I try to make him understand that there are times I can't, and he thinks I'm saying won't!

Caregivers should not only realize that being able to do something does not mean being able to do it all the time, but to also work with the child towards awareness of this phenomenon and its influence on daily decisions. A pattern of intense activity periods followed by crashes is common among autistic people, sometimes the only way to get things done. Caregivers can take this into account by including downtime periods in the schedule, and again, by teaching the child to identify this pattern.

Finally, the possibility of losing skills or abilities should be kept in mind. Loss of abilities in normal people is common during middle-age and old age but can happen to autistic children and adults on various ages. Sometimes there is a tradeoff in gaining and losing skills. For example, teenagers who gain communication or social skills may lose savant skills they had in childhood. When setting short-term goals, it is important to try to anticipate their long-term implications.

Meaningful relationships

Some autistic adults remember learning things mainly on their own in childhood. Ava writes about

... learning so much about the world for ourselves from first-hand experience, before learning about faces and the human-social-world attached to faces. ... Knowing things because someone tells us it's so is for us a secondary thing, coming later in our lives, and also shakier since it's based on opinions versus direct experience.

However, learning may be much faster and more effective, if the child can learn from adults. The educational process is based on a meaningful relationship between child and caregiver. The theory of mediated learning highlights the role of a mediator, who intervenes between the learner and the stimulus to be perceived by the learner. In addition, meaningful relationships may be a long-term goal that the child may foster when growing up.

A meaningful relationship is established by mutual sharing of meanings. When aiming to teach the child some piece of material, meaning is usually conveyed from teacher to learner.

However, when the goal is to let the child experience and practice relating to another person, meanings should flow in both directions. It is highly important to realize and accept autistic ways of relating, as well as typical autistic meanings.

A meaning is a story we tell about an object or an action. A common normal way of giving meanings to an object is to take it as a symbol for something else, usually something connected to people and relationships. For example, a doll plays the role of a baby, and a circle is a symbol for a face. For autistics, the meaning of an object may be the object itself: its physical, sensory characteristics. Donna Williams calls this experiencing way *simply be*. It is OK for a caregiver to share a normal meaning with an autistic child, but it should be done in a way that respects the differences: "this is what it means to *me*, and I acknowledge and accept that it means something else to *you*." The caregiver should bear in mind that attaching social connotations is not natural for the autistic child, and should not present it as the only legitimate way of relating.

The process of relating should allow for autistic differences in terms of duration and distance – both physical and emotional. In particular, the role of feelings should not be assumed to be the same as in normal children, nor should there be a goal of changing the internal mechanism of the child to be more normal. Finally, the child should be given a chance to experience connections with other autistic people of various ages, in an autism-friendly environment.

Teaching skills

When setting short-term goals for acquiring skills, one should bear in mind that skills are not goals in themselves but are means to enable the person to achieve goals. Therefore, priority should be given to skills that would maximize the autonomy of the person, rather than to skills typical for normal age peers. It is useful to teach a teenager the technicality of riding a bus only if the person is likely to be able to take buses. If the teenager has severe self-control problems that require constant supervision, then the likelihood of taking a bus alone is very low and other skills have a higher priority.

The professional autism literature describes some characteristics of learning styles abundant among autistic people: concreteness, need for many examples and clear instructions, preferred modality, and other autism-related issues that should guide caregivers and teachers to maximize instruction efficiency. From an autistic point of view, an additional issue is highly important: One of the autistic coping strategies is robotic functioning, often referred to as autopilot mode. Some autistic adults mention this phenomenon as an undesired result of NT pressure, something they want to get rid of. Teachers should be careful not to push the learner into autopilot mode and not to confuse robotic functioning with successful learning.

Choosing interventions

An intervention is a tool for achieving a goal. In principle, a certain method can be used for various goals, or one can work towards a certain goal using various methods. In practice, certain interventions are identified with specific goals, but we don't have to follow this connection. We can foster the goals described above, choose from each intervention effective elements that suit the child, and integrate them into a holistic treatment plan.

The professional and parents-oriented literature has abundant descriptions of treatment methods. This article briefly mentions some widely-used methods mainly in the context of long-term goals.

Treatment- paradigms

If eliminating autism is not a goal, one can wonder why the child needs a treatment plan. The answer is that every child needs love, attention, and thoughtful guidance. Parents are supposed to know how to treat normal children (though this is not always a justified assumption) from their experience with their own parents and from observing other parents. When the child is autistic, both the parents and the educational system cannot use their usual tools. Treatment paradigms offer general ways of relating to the child. These methods aim to teach skills by changing the child's environment. Examination of each method includes the following questions:

- What is the perception of autism at the basis of this method?
- What is the main long-term goal?
- Which elements of this method can be employed to work towards our goals?
- Which elements of this method are inherently incompatible with our goals?

Behavioral methods, like Behavior Modification or Applied Behavior Analysis (ABA), are based on Skinner's ideas of the organism's response to stimuli. Teaching skills is done by encouraging desired behaviors (by positive responses) and discouraging undesired behaviors (by negative responses). There is no specific assumption about the nature of autism, because this method is concerned mainly with behaviors and not with internal mechanisms.

Caregivers who employ this method usually opt to normalize the child, but parents who accept their child as autistic have used elements of this method to help their child gain more autonomy.

Some positive elements of this method are:

- It is highly structured.
- Discrete Trial Teaching, which breaks up tasks into small stages and teaches them systematically, increases the chances for success.
- Behavior analysis examines the environmental causes for undesired behaviors, thus helps to design an environment to maximize the child's learning.

If taken to extreme, or if not supplemented by other treatments, this method might be harmful:

- Negative responses might be too painful for the child, sometimes bordering abuse. For an auditory sensitive child, even a loud "no" can be painful.
- Some users of this method advocate an intensive treatment schedule, sometimes as many as ten hours a day, disregarding the child's need for downtimes.
- Learning method is automatic, and does not depend on conscious processing by the learner. This way, the child learns some behaviors but not why these behaviors are desired or when to use them.
- Instead of developing self-awareness and self-monitoring, this method induces autopilot functioning.
- If used with no combination with other methods or therapies, important needs such as sensory ones may be neglected.

Relationship-based methods, like play therapy (Greenspan) and Relationship Development Intervention (RDI), highlight the importance of interactions between child and caregivers. Comparing social and communication development of autistic children with that of normal peers, the essence of autism is defined as developmental deficits in these areas. Treatment aims to minimize these deficits by allowing the child to experience positive interpersonal exchanges and encouraging interactive responses by the child.

Some positive elements of these methods are:

- They consider internal states of the child, including sensory and motor-planning issues.
- Caregivers are guided to identify the child's preferences and follow them, aiming at mutual enjoyment.
- The essence of communication is highlighted, rather than the technicalities of communication.

Drawbacks of these methods, as currently employed, are:

- They opt to normalize the child's internal world, as well as behaviors.
- They ignore autistic ways of relating and assume that the only way of making connections is the NT one.
- They do not respect the child's need for downtime, including solitary play.
- Autistic typical behaviors, like perseveration and stimming are perceived as anti-social, and thus short-term goals include elimination of these behaviors.

Therapies

Therapies use a specific channel or discipline to address a specific deficit or dysfunction of the child. Many special education programs employ therapists from a variety of disciplines, like occupational therapy/sensory integration, speech-language, or Music / art / movement / physical therapy etc. All of these methods may be helpful to address the child's needs (e.g., sensory needs), help the child understand the essence of communication and interaction, or teach useful skills. Since autism is not a disease, therapies should not be expected to "cure" the child or get rid of autistic characteristics.

It is now widely recognized that autism is not an emotional disturbance, so psychoanalysis is not recommended for autistics. However, psychologists still treat autistic children and adults (besides performing evaluations). Autistic children and adults may need psychotherapy in crisis situations, as any other person might. Again, the psychologist should respect autistic communication and internal mechanisms and not try to impose normal ways of relating on the autistic client. This is important also in the case of therapies like art and music, which are sometimes used as means to approach the client for psychodynamic purposes. Many autistic clients would not benefit from being pressured to use their imagination or discuss their feelings. Cognitive therapy has the best potential for helping autistic people.

Generally speaking, autistic children need acceptance and guidance rather than emotional support and protection. Therapy is helpful inasmuch it is viewed as an effective teaching method. Sinclair writes:

A professional at the conference remarked that therapy with an autistic person is educational therapy, not psychotherapy. Call it educational therapy, interaction therapy, common-sense-explanation therapy--or just call it honest and direct communication.

Biochemical interventions

Various diets and dietary supplements have been tested by parents seeking a cure for their autistic child. This cannot be an argument against using these methods. If a child is allergic to some foods (or other substances), then the problem should be treated from a purely medical point of view, regardless of the child's autism or normalcy. Before starting a diet or even checking whether the child needs one, there should be some symptomatic indication (autism is not one!) that the child has a medical problem. Parents can ask themselves: "Would we pursue this direction if the child were not autistic?"

The same reasoning applies to psychiatric medicines. If there is an indication of a psychiatric problem (e.g., anxiety or obsessive thoughts) causing the child distress, then medication can be used, along with careful examination of the child's environment, to relieve this problem. Medications should not be used to "cure" autism, eliminate autistic behaviors (e.g., perseveration), or make the child easier to control. In particular, medication might be dangerous if the child does not have enough communication skills to report reliably on the effect of the medicine, because external observations (e.g. body language) can be misleading.

Choosing educational settings

The following paragraphs discuss some parameters to consider when choosing a program for the autistic child, in addition to the treatment methods and the available therapists employed in the program. It is important to collect information about the program, but also to bear in mind that the names of treatment methods may not describe accurately their actual implementation. A sensitive, open-minded kindergarten teacher in a "behavioral program" may be found more helpful for the child than a rigidly doctrinarian therapist declaring she fully accepts every child for who he is.

Educational vs. therapeutic

Since autism is not a disease and autistic kids need education and learning skills rather than healing, an educational program (a school or a kindergarten) seems more appropriate than a therapeutic one (e.g., a psychiatric day-care). As mentioned above, one should check whether a special school actually focuses on teaching rather than filling the day with various therapies. On the other hand, some programs for toddlers and young children calling themselves therapeutic kindergartens are in fact similar to regular ones but with smaller classes, autism-trained staff, and supplementing therapists. These may be very helpful for young children who need a lot of one-on-one instruction.

Inclusion vs. segregation

As mentioned above, contact with other autistics of all ages is important for the child to develop identity and meaningful relationships. Physical proximity of other autistics is almost automatic in segregated programs for autistic children only, but that does not ensure meaningful connections between them. To make segregated programs advantageous, the staff has to be not only well informed about treatments, but also respectful of the children's autism and not intent on forcing them to behave normally. On the other hand, the purpose of inclusion should be not normalization, but teaching how to navigate the normal society.

Some points to consider are:

- **Message conveyed:** Preferring integration might convey the message that only normal peers are worth connecting with; segregation might mean that the child must be protected from the general society.
- **Environment:** In segregated programs, it is easier to design the environment to meet educational and sensory needs of the autistic children. Normal peers in integrated schools must be given guidance and support; otherwise they might reject the autistic children or even bully them.
- **Educational opportunities:** Segregated programs are usually smaller and serve students with highly diverse abilities; therefore the variety of academic experiences available to a student with specific learning style and interests is limited much more than what is offered in regular education.
- **Staff expertise:** A program for autistic children gives staff more opportunities for developing expertise and learning from colleagues; Teachers in integrated settings are more informed about the regular curriculum and activities.
- **Staff expectations:** Teachers in special education tend to have lower expectations from students, partly because they lose contact with normal standards. Teachers in integrated settings might push autistic students for normal achievements.
- **Exposure to normative environment:** The environment in segregated programs might be too accommodating of autistic needs (quiet, structured, predictable) so that students do not learn to cope, and their possibilities later in life are limited. The environment in integrated programs might be so challenging for autistic students that they may not have a chance for effective learning.

When learning about programs, one has to find out whether the potential strengths of each kind are really developed and what is done to counteract potential weaknesses. Integration is a continuum; therefore there are ways to combine strengths from both types. For example, a small special education class in a regular school may give the autistic students both contact with autistic peers as well as access to regular academic curriculum and some experience of navigating the general society.

Academic vs. vocational

It is true, that academic skills alone are not enough in preparing an autistic child for adult life. Some autism experts underestimate the importance of formal or academic education. Unless the child is bright enough to be expected to graduate college, these experts recommend discontinuing academic studies and focusing on life and workplace skills when the child reaches adolescence. However, academic or "formal" education may be particularly useful for an autistic person:

- **Vocational:** Many autistic people who have motor or sensory problems would do better in "white-collar" jobs (e.g., clerical work, computer programming) than in "blue collar" jobs.
- **Life skills:** Unlike their normally developing peers, autistic children and youth do not absorb general knowledge from friends and the media. They may find it easier to learn about society and relationships in the more structured, explicit framework of curriculum.
- **Mental patterns:** Formal education uses structured patterns that may help in formulating a problem or a situation. Where normal peers can use emotions and intuition, an autistic can use these patterns.

- **Culture:** An important part of formal education is related to culture and heritage: literature, art, history, and other humanities. Autistic children and youth have the right to access these treasures, like any other child or teen.
- **Leisure activities:** Some of the subjects taught at school may develop into hobbies or special interests.

Daily life

Daily life is a series of decisions either planned ahead or ad-hoc reactions to situations. The caregiver's outlook is reflected in every decision and reaction. The message conveyed to the child, and the whole educational process, are the accumulated results of a series of decisions and reactions. It is therefore highly important for caregivers to be aware of their own perceptions.

The following example illustrates how responding to the child's behavior relates to long-term goals. While waiting for the school bus, my son is pacing back and forth, talking to himself. What should I do about it? According to the protective-passive approach, I should do nothing: he is unaware of his difference, and I am here to intervene if passers-by have a problem with it. According to the dynamic-normalization approach, I should tell him to stop, because self-talking is weird and he should (and can) adapt to normal standards. According to the identity-goals approach, I should leave him the choice. Therefore, I approach him and ask: "are you talking to me?" When he replies "no," I explain: "most people do not talk to themselves. They talk when they want to say something to someone else. Therefore, when you talk to yourself in the presence of others, they may think that you are talking to them. They are likely to respond to whatever you are saying." On other occasions, when he is in my presence and I am not sure whether he is talking to me, I ask him. Sometimes he would say "yes," sometimes he would say "no, I was just talking to myself."

By talking to him in this way, I alert him to what he is doing and how it may be perceived by others. I raise his awareness of his differences but do not label his difference as bad. It is up to him to choose whether to monitor his natural processing or to remain his own self and be prepared to deal with responses from other people.

Conclusion: the essence of care-giving and of self-care

When people learn that I have a special-needs child, I tell them that parenting a special-needs child is essentially the same as parenting a normally-developing child, but more of it: I face the same dilemmas, but more acutely. Every caregiver deals with uncertainty, preparing a child for an adult life in an unknown future. But for disabled children, the uncertainty is bigger, both in terms of developing abilities in the child and the availability of services when the child grows up.

Caregivers must be highly self-aware and constantly check their decisions and behavior: Am I acting for the child's well-being? Are these my goals or the child's goals? A helpful strategy is to accept the child actively by learning about his or her disability and by acknowledging and respecting the differences between child and caregiver.

Caring for a child involves a delicate balance between the child's dependence on the caregiver and the long-term goal of teaching the child to be independent. One way of doing

that is to introduce the child to various options, to teach the child to learn about the consequences of each option, and to let the child decide.

Acceptance and goals are helpful concepts for autistic adults too. First of all, I accept myself for who I am and get to know my inner processing. Then, I seek for the particular balance between being myself and functioning in an NT world, to find a way that would best enable me to achieve my personal goals.

Further reading

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