

## **Chapter 14 Autism and Society**

### **1. Locating the Problem**

For most of society, the autistic child is not only a mystery, a conceptual problem, but a practical problem as well. Whether he is mentally handicapped or has normal intelligence, he doesn't behave like other children. He can't be taught like them and won't obey or cooperate. He is a burden to his parents, a nuisance to his teachers, an unwelcome intruder into the world of other children. There are indeed many who wish he had never been born, though few would ever admit it. They see autism as a disease, harmful to the individual and a blight to the society in which he lives. The solution they envision is a cure that would transform the autistic child into a normal one.

But how does the autistic child himself see it? Those autistic children whose intelligence is normal or above certainly must have their own opinions of the situation, and even those who are moderately mentally handicapped are sufficiently aware to have some feelings about it. Are their opinions any less valid than those of the normal members of society? What do they think of it?

For the autistic child, the problem lies not in himself but in society. Society is unfriendly, irritating and chaotic. It is normal people that are unreasonable and stubborn. It is their demands and behaviour, not his own, that are the source of the problem. If they would only leave him alone everything would be fine. It is society that is diseased and that needs to be cured.

One of the great milestones eventually reached by most intelligent autistic children is the realisation that the way he himself behaves and thinks has something to do with the problems he is having. But even those who have achieved this insight still feel that it is society, not themselves, that is at fault. He is, after all, simply going about his own business. What right have others to interfere? The autistic perspective of autism is therefore exactly the opposite of that of society. What both agree is that there is a problem. It is their different perspectives that makes their understanding of the nature of that problem so radically different. Which is correct?

There is clearly some truth in both perspectives, but neither is complete. The real location of the problem is neither in the autistic child nor in society, but in the interface between them. The autistic person does not match society. Like a round peg in a square hole, he does not fit. The fault, however, is neither in the peg nor in the hole, but in the attempt to put them together.

This final chapter is very different from the rest of the book. It contains little new about autism itself. For the most part, these are implications of what we have discussed in earlier chapters. Nor is this an attempt to fully develop the complex social issues raised by autism but just to make some brief points and suggestions, material for further thought and discussion. The focus is less on what the relationship between autistic individuals and society actually is and more on what it ought to be. The emphasis in this chapter is on those of normal intelligence or above, not because the social questions posed by those who are mentally handicapped are less important, but because the issues they raise are more ones of society's relationship to mental handicap than to autism per se.

#### **1.1 The Individual and the Social Group**

Since the problem that autism poses is a product of the combination of the autistic person and the society he is in, to understand it we must first understand certain things about the nature of the human social group. Every social group that exists in nature, whether ants, elephants or human

beings, develops according to the nature of the individuals of which it is composed. No group can exist unless its nature is compatible with that of its members. As social systems evolve, they make free use of the capabilities of their members, and tend to develop up to the limits of those capabilities. In the case of human beings, since the overwhelming majority of infants have innate interests in human features and innate tendencies to respond in certain ways to various stimuli, the social systems that evolve assume that all members have those qualities. The need for these innate qualities becomes part of the structure of society itself and therefore a requirement of functioning within it. For individuals who lack any of these qualities, the social structure will therefore inevitably present problems.

As we have explained, adult behaviour is the mature stage of a long sequence of infant and child behaviours, each developing from the one that preceded it. Although neither the steps of the sequence nor the final products are exactly the same in all cultures, all involve sequential developmental processes. The mature state can never be reached straight away without a progressive sequence.

Behaviours in the mature state often seem simple when in fact they are extremely complex. Consider a basic behaviour such as greeting. When and how it is appropriate to greet another person is a function of many factors including what the greeter himself and the one he is greeting are occupied with at the moment, their relative social status, and how long it has been since they last greeted one another. Responding to a greeting can involve additional complexities. In a given situation there may be a range of acceptable greeting-behaviours, and responding correctly involves not only understanding the situation, but also knowing an appropriate response to each possible greeting. Furthermore, selection of the appropriate response must be automatic, because the response must be produced without hesitation. Ability to compute the appropriate behaviour analytically is therefore not sufficient. Both initiating and responding are therefore complex behaviours, and their production is a skill that is acquired gradually through an extended course of development.

Since innate qualities play key roles in each of the developmental steps, lack of any one of those qualities may result in failure to proceed from one step to another and therefore to reach the mature state. In particular, since it is through social interaction that an individual advances from one step to the next, the course of development can be compromised simply by weak inclination to interact socially. The mismatch between the autistic individual and society is therefore inevitable. Whatever the innate source of his autistic behaviour, it will result in failure to fit into society, to become a normal member of the social group.

## **1.2 Coordination**

At first, the conclusion that these problems are inevitable might seem discouraging, shattering any hope we might otherwise have harboured that they might disappear by themselves. But of course, no such hope has ever been realistic, for never in our experience has it been fulfilled. Autistic children never “just outgrow” their autism and become normal. This analysis should therefore be seen, on the contrary, as the first real glimmer of hope, for it gives us, for the first time, an informed approach to the problem. If the locus of the problem is neither in the autistic individual nor in society but in the interface between them, then the solution is neither to cure the individual nor to alter society, but to learn to reconcile them.

In the first chapters we identified the central trait of autism as lack of coordination with other human beings. Now we see that it is not only with other individuals that the autistic individual is insufficiently coordinated, but with society as a whole, and that it is lack of coordination with society that is the essence of the practical problem of autism. For it is the

nature of the human species that no individual can function or even survive in isolation. Though he is not as completely subordinate to the group as a bee, neither is he as completely independent as a turtle. A human being is an individual with an individual identity, but an essential part of his existence is membership in the social group.

What the autistic individual therefore needs to do is to learn to coordinate himself with others. Unlike attempting to alter his innate autistic nature, which is essentially impossible, learning to coordinate with others, though difficult, is an attainable goal. It is, indeed, a process that every normal individual goes through, for as an infant no human being is innately coordinated with others. Over the course of development he gradually coordinates himself until he reaches an acceptable level. The crucial difference is that while normal children do this naturally without intention or effort, the autistic child does not, so he has to work on it. But the aptitudes called for by this process are the same ones used in other developmental processes, and to the extent that an autistic child can develop other abilities, he can develop this one too. He may need help, encouragement, and even some coercion, but he can do it. Unlike the round peg and the square hole, he is not essentially incompatible with society. The mismatch is dynamic, not static. It is not in the parties themselves but in the way they behave toward one another.

It is also encouraging to realise that coordination does not need to be complete. Indeed, no normal individual is completely coordinated, either with the group as a whole or with any other individual member. There is a certain minimal degree of coordination that is necessary, followed by a range in which increased coordination is beneficial, and beyond that range increased coordination is of little advantage. The goal for the autistic child is therefore not to achieve perfection but only those minimal kinds of coordination that are necessary to function in society.

## **2. The Variety of Human Social Structures**

Unlike other species, whose social structure is determined by heredity, the human genetic composition allows for a variety of social structures. All share certain basic patterns and qualities while varying in others. Among the variations are the kinds and degrees of coordination that they require of their members. How well an autistic individual fits into society is therefore in part a function of the nature of the social structures of the particular group of which he is a member. That is to say, some cultures are more autism-friendly than others. We cannot, therefore, speak of how autistic individuals fit into 'society', but rather of how different kinds of autistic individuals fit into different kinds of social groups. Though we cannot attempt to describe all the various social structures that exist, by considering certain basic patterns we can get an idea of the range of variation.

### **2.1 The Tribal Village**

The most natural human social structure may be described as the *tribal village*. It consists of a hundred or so individuals living in family groups and joining together according to various traditional social patterns to obtain food, protection and other necessities of life. This sort of structure has been found throughout the world in cultures with stone-age technologies. It is not, however, limited to primitive cultures. Even in cultures with higher levels of technology and larger cultural structures, variations of the tribal village structure continue to emerge in sub-groups. From feudal villages and free peasant and agricultural communities to city slums, individuals tend to organise themselves in ways characteristic of the tribal village.

In the tribal village, each individual is known by all the others. They bear certain known relationships to one another and there are certain established conventions and rules of behaviour. In that an autistic child born in a tribal village receives certain kinds of help and support, this primitive social structure may be considered autism-friendly. He lives within a family unit which is part of larger concentric units up to the entire village, so he is cared for and never in danger of becoming an anonymous wanderer. Everyone knows him and they all know what to expect from him. If an appropriate role exists for him he is channelled into it, and since in most such cultures there are enough routine manual tasks that can be performed even by one who is mildly mentally impaired, he can become a productive member of society. He is provided with food, clothing, shelter and perhaps even a spouse.

In most cases, however, those benefits are outweighed by the challenges with which he is confronted. While in times of peace and plenty he is cared for along with everyone else, cultures that have little control over their environment regularly suffer from periods of shortage in which members compete with one another for necessities of survival. In such times the autistic child, along with other handicapped children, will be among the last to receive food and protection and the first to die. Few, therefore, survive to adulthood. Even those who have the aptitude for normal intelligence may die young if they fail to actualise that potential early enough.

Furthermore, for most autistic children, life in the tribal village is not conducive to optimal cognitive development. In the tribal village, much of a child's time is spent in the peer group without adult supervision, and it is there that he develops cognitively and socially. Unless he has siblings to help and protect him, this is an inhospitable place for the autistic child. Other children are not as ready to make the sort of allowances for him that family members are. He is left out of their games even if he tries to participate, and if he does not, no attempt is made to draw him in. So, while other children are playing together and their cognitive growth is being guided and stimulated, the autistic child is playing by himself or is at home performing menial household chores. For many autistic children this means very little cognitive development. When they become adults they are therefore largely lacking in the social skills of their culture and even in many of the physical ones.

The tribal village also tends to be culturally rigid and narrow. While this may be good for the autistic child in that the stability and predictability are a source of comfort and security, there is little tolerance for idiosyncratic behaviour or lack of social skills.

## **2.2 Modern Social Structures**

Larger social groups are a relatively recent phenomenon. The social structures found in cities, kingdoms and empires, which first appeared several thousand years ago, are radically different from the tribal village, and members have different kinds of relationships to one another. There is a tendency towards anonymity, especially in subgroups such as armies and slave labour gangs. The sort of competition for survival that in simpler societies occurs only in times of famine may be a perennial condition. Additional social skills, "street-smarts", are essential, and autistic children who might have survived in the tribal village fall by the wayside, casualties of the advance of civilisation.

Not all modern social structures, however, are bad for autistic members. Firstly, there is a tendency for subgroups of tribal-village size and structure to form within them. As far as the specific needs of autistic members are concerned, a small farming community within a modern western country has most of the same qualities as a stone-age village in the jungle. Secondly, there are some new social structures within which certain autistic individuals may feel relatively comfortable and function well. Bureaucratic positions and repetitive factory jobs, for example,

give some autistic members the regularity they crave. Evolution of social structures is therefore sometimes beneficial and at other times detrimental.

Changes in social structures were among several factors that converged in the twentieth century to lead to the recognition of autism as a distinct syndrome. Deterioration of the coherence of extended families and the replacement of stable communities by impersonal transient ones left autistic children and adults without a natural social support system. Advances in technology eliminated many of the routine manual jobs that they had previously performed. Unlike earlier social structures, in which autistic and other mentally abnormal individuals were accepted as part of the world and their presence was not seen as a disruption for the larger society, in modern society they are a problem that must be dealt with in one way or another. In a farming community, the autistic adult who milks the cows every morning and evening and brings in wood for the fire needs neither institution nor therapist. Indeed, to all but his family and neighbours he is invisible. It is only when there is no longer any place for him within society that his existence becomes an issue.

In modern society the autistic child, rather than being left at home to settle into an appropriate niche within the family, is thrown into a school system where all children were expected to behave similarly. Though perhaps more benevolent than the children's group in the tribal village, it is more rigid and demanding, and most significantly, there is no escape. He is not permitted to run home or go off by himself. For many autistic children school is their first introduction to a society that will be a source of continual irritation and stress for the rest of their lives. Conversely, it is in school that society first discovers the autistic child and that he begins to be a problem for them. From that moment on society, too, will continue to be disturbed by the autistic member who does not fit in.

### 2.3 Niches

In many cultures, both primitive and advanced, special niches develop in which autistic members can participate in society. In some they may even be able to make valuable contributions to the group. In many primitive cultures there is a role of *shaman* which is suitable for certain kinds of autistic individuals. Though it did not evolve specifically for them, and indeed, most of those who fill it are not autistic, it is a role into which some intelligent autistic individuals naturally fall. The shaman is at once a skilled practitioner of traditional medicine and a link to the spirit world. In some of the cultures in which such an institution exists, children who play by themselves rather than participating in games with the others, especially those who independently develop unusual skills, may be seen as being guided by supernatural forces and therefore channelled into this role. This identification and subsequent channelling are performed not by any individual member but by the culture itself. In various periods in the course of evolution of Western Civilisation, the roles of monk, scholar and scientist have assumed similar functions for intelligent autistic children. Though radically different in many ways, in these roles too, skills at which autistic individuals excel are valuable while social skills in which they are deficient are less important.

Niches such as these were never deliberately created for the sake of autistic members. Artificial creation of positions to provide the handicapped a place in society is a fairly recent phenomenon. Traditional cultures do not even consider the possibility of modifying themselves, and certainly not of creating new institutions or roles. New roles evolved because society had need for them and conditions in the culture were conducive to their emergence. Only after they existed did they come to also serve this special function for autistic members.

There are other kinds of niches which, although they do not give the autistic individual the opportunity to be appreciated for his special qualities, at least provide him a refuge in which he can survive and participate while being protected from the demands of normal social life. Some simply assign him an identity so that he no longer seems strange and threatening to others. They provide him with a role by which others can identify him, a pigeon-hole into which to place him, thereby making him acceptable to society. In most cases the autistic individual does not choose or adopt these roles himself. They are imposed upon him by others, sometimes by the social group as a whole. Once having been cast into them, however, he may be moulded by the way others treat him and his own self-image and personality develop accordingly.

Most common is the role of *village fool*. This is really a role for those who are mildly mentally handicapped, most of whom are not autistic, but autistic individuals who function below the normal level of intelligence, whether because of essentially limited aptitude or lack of development, fall into it as well. Another role, this one being appropriate for a wide range of intelligence, is that of *hermit* or *recluse*. Ironically, in some cultures the latter may be less socially accepted than the fool, and some more intelligent autistic members may prefer to play the role of fool to receive better treatment.

In contemporary society, especially in Britain, the role of *eccentric* is available to those of normal intelligence and above. It exists across different social classes and different levels of professional accomplishment, so it can take in a wide variety of autistic individuals as well as many who are not autistic. Since eccentricity is recognised as being compatible with ability and success, it does not carry the same kind of stigma as the others. Related roles, such as *nerd* and *absentminded professor*, especially in America, are mildly negative.

But no matter how negative or limiting a niche may be, it is better than no niche at all, since it saves him from being a social outcast. Autistic children who grow up in cultures that have no niche or social role into which they can fit are left to do their best trying to function as if they were normal. Most fail dismally. Some, as adults, manage to find a mode of getting along with society, but it often comes only after enduring a childhood of rejection by peers and punishment by adults.

### **3. Group Identity and Bullying**

Human populations naturally grow and expand, and as they do, they eventually come into conflict with one another over territory and resources. For a group to survive, individual members must unite to form fighting bands to defend themselves and overcome competing groups. These bands require cooperation and coordination, and are invariably composed of leaders and followers. One of the main goals of social development during childhood and adolescence is to prepare for the formation of such bands. Each child learns to recognise the roles for which he is suited and develops skills and attitudes appropriate to those roles. Each also learns to recognise the qualities of each of the others, so they know how to treat one other and what to expect from them. Children's games and sports are designed to train members to fit into the fighting band later on. The teams they form are models for the band that will later fight together and defend one another and the rest of the community to which they belong.

By late adolescence or early adulthood the group has been solidified. It is composed primarily of individuals who have played together since childhood. As well as roles of leaders and followers being recognised by this time, individuals have established bonds of friendship and group identity. This is the last stage at which a newcomer can join and be considered a full-fledged member. Beyond this age not only will he be rejected by the group, he himself will no longer be able to change his self-identity to see himself as one of them.

One unpleasant but necessary part of the formation of the fighting band is the elimination of individuals who will not be able to play effective roles in the band and who will therefore be a liability to the group. These include both those who are physically unable and those who cannot learn to coordinate themselves with the others. This elimination is accomplished by a combination of various natural mechanisms. Children are endowed with the ability to identify those that do not fit in and are inclined to target them and attack them. Under appropriate circumstances they kill them or relentlessly hound them until they are harassed to death.

Bullies, children who take unfair advantage of those who are weaker than them, are particularly suited for fulfilling this function. Most bullies suffer from emotional problems which interfere with their maintaining normal relationships with others. They are frustrated and vent their frustration on those who are weaker than them. Few are actually liked by other children, although some have sufficient social skills to manipulate others and avoid sanction. Even those who lack such skills, however, know enough to avoid overstepping their limits and offending the group, since no matter how strong they are, the others could unite and overpower them. They therefore prefer to target children who have been rejected by the group and will not be defended by the others.

The phenomenon of bullying is therefore beneficial for the human species, in spite of its generally negative character. In addition to assisting in the elimination of misfits, the bully serves as a test of potential leaders for their ability to control him. He thus contributes not only to the formation of the fighting band but to the broader process of establishment of social order. Here again, the autistic child is a casualty of a natural phenomenon that is beneficial to the species as a whole.

In larger and more complex social structures such as cities, kingdoms and empires, however, social coordination, while just as important as in the tribal village, assumes different forms. Conscription and professional armies replace the organically formed fighting band. Division of society into social classes exempts some members from the responsibility of defending the group and assigns them other roles. Members who cannot coordinate with the others are not necessarily liabilities any more, and some may be able to make significant contributions. But the biological nature of the human being does not change, and those social behaviours that are derived from it do not cease to exist. Only their expression changes, in accordance with the new social structures. Band-formation and bullying, though they no longer serve their original functions, continue to exist in one form or another. In modern western society, the bonding by which the primitive fighting band was formed is replaced by the formation of social relationships, life-long friendships and loyalties. Instead of the primitive hunting-party, institutions such as university and army become the sites of that formation.

Efforts to eliminate or even modify these natural social phenomena meet with strong resistance. Although in modern society identification with subgroups tends to undermine social unity, it persists. Almost all individuals see themselves as members of at least one subgroup, and very few simply as citizens of the international community or even of their nation. Bullying, too, persists even though it no longer serves its original purpose. Censure by adults is of little effect, because children live by their own standards. It is ultimately the child-culture, not the culture of their parents, that determines whether bullying persists and what form it takes. In some child-cultures bullies find themselves detested and shunned, their victims treated with sympathy, and those who protect them respected. In those, bullying is minimal and not a serious problem. In most, however, the bully, while personally feared and hated, is also admired and respected, so the natural phenomenon is not curbed. Other children vicariously enjoy his aggression, because they secretly would like to hurt others as he does but are unable or unwilling to do so.

Being the victim of bullies is one of the experiences that can permanently scar an autistic child and radically alter his social development. Social interaction, stressful for autistic children even under normal conditions, becomes painful and frightening. His natural disinterest in other human beings changes to fear, aversion and hatred. Unless he happens to be the child or younger sibling of a strong leader who is respected or feared, or is protected by some unrelated child who favours him and takes an interest in him, the autistic child will inevitably be among the bully's prime victims. Even those autistic children who are strong enough to defend themselves physically are often socially out-manoeuvred by their oppressors, who make them appear to be the aggressors rather than the victims, and they find themselves blamed and punished by the adults who should be defending them.

#### **4. The Autistic Individual as an Asset to Society**

Hans Asperger had high regard for the autistic children that he treated, and considered their potential superior to that of normal children. Though perhaps overstated, his opinion is confirmed by the achievements of numerous outstanding autistic individuals, past and present. Especially in the more abstract fields such as physics and mathematics, some of the greatest strides in human progress have been made by those who, in retrospect, have been diagnosed as autistic, including two of the most creative minds in history, Newton and Einstein.

One might be tempted to suggest that autism evolved precisely because of its value for the human species as a source of innovation and progress. Those who are given to sensational speculation might even suggest that the sudden spurt in civilisation some five thousand years ago, after seeming millennia of stagnation, was the result of a mutation that produced autism, and that those autistic individuals who are not endowed with superior intelligence are but an unfortunate by-product. There are, however, serious flaws in this romantic scenario. It is only in the past three hundred years or so that technological innovation has been an important factor in the evolution of culture. Before that, progress was slow and sporadic. New techniques were windfalls, discovered accidentally. To say that a condition that increased original thinking was a benefit to the human species prior to that time would therefore be an anachronism. Furthermore, originality is not the unique domain of autistic geniuses. Social training does not preclude original thinking, so normal human beings are not hopelessly condemned to following the crowd. Acceleration of cultural progress has been brought about by changes in the structures of culture itself, not by biological changes in its bearers. Once a culture becomes willing to accept new ideas, anyone, autistic or not, can contribute.

Nonetheless, recognition of the significance of the contributions of autistic individuals to civilisation radically changes our perspective of the phenomenon of autism itself. Not only is it no longer a disturbing enigma, it now takes its rightful place in the vast panorama of human variation. Equivalently, we may say that this is an insight into social learning itself. Even though social learning is essential for the human species, it is also detrimental in some ways, so the occasional failure of social learning and the creativity that is thereby released can be beneficial for the species.

But what of the vast majority of autistic individuals who do not have the capacity to become great thinkers or innovators? What is their place in society? While they do not, by and large, bring any special benefit, they still have the potential to be contributing members. How a particular autistic child actualises his potential is to a large degree a matter of how he is treated by those around him, especially the education and opportunities he is given. In this he is like any normal child. The difference lies, of course, in the details. What is good for other children may not be good for him. His needs are not necessarily greater, but they are certainly different. Above



all, he needs the guidance of caregivers and teachers who understand his condition and know how to reach out to him and communicate with him in ways that he is able to understand and accept. But whatever assistance a particular autistic individual may need, whether as a child or after he has become an adult, is a worthwhile investment for society, because if he can become a productive member rather than a burden, society as a whole benefits.

## **5. Bridging the Gap - Integrating Autistic Members into Society**

Since the problem of autism lies in the interface between the autistic individual and the society around him, each side can, and indeed, should contribute to its resolution by adapting to the other in those ways that it can. At first, during infancy and early childhood, the burden of accommodation lies entirely upon society. Over the course of development it gradually shifts, until, by adulthood, the overwhelming burden of bridging the gap falls on the autistic individual himself. Ideally, the autistic adult should be able to go out into a world that is not sympathetic and does not understand him and interact with those who do not reach out to him. While friends and relatives will continue to accommodate him and help him when he is in need, he should be able to hold his own among the vast majority who do not. For those many autistic individuals who do not reach this goal, society must continue to bear a degree of the burden.

Each should also be aware of the limitations of the other and respect them. Society should not expect autistic members to transcend the essential limits of their condition, but neither should the autistic member expect society to change in ways that would be an unfair inconvenience for the majority. For society, accommodation is based on understanding the needs of autistic members. There will always be autistic children, and as some grow up and require less help, new ones are born to replace them, so the need to accommodate never diminishes. For the autistic child it is a different thing altogether. As an individual, his own relationship to society is continually changing. Improving his accommodation to them is a dynamic process of learning and development.

In that the autistic child is learning to adapt himself to society, he is no different from other children. Being a socially acceptable individual does not come to anyone by nature. It can only be acquired through development. All need to learn skills for getting along with other human beings, and until they do, others need to adapt themselves to them. The difference is that whereas normal children are innately attracted to other human beings, naturally interact with them, and are inclined to be moulded by those interactions, autistic children are not. The process of learning and development is therefore more difficult, takes longer, and requires more assistance. Others need to accommodate more to an autistic child than to a normal child of the same age.

### **5.1 A Philosophy of Education for the Autistic Child**

This gives us an important perspective on the education of the autistic child. Neither goals nor approaches are the same as in the education of the normal child. The goal is not to make him normal, for that is impossible. Nor is it to try, having accepted that impossibility, to make him “as normal as possible” within his limitations. It is, rather, for him to learn to get along with other people, to be comfortable with them and behave in ways that make them comfortable with him. His own individual personality, of which those qualities that make him autistic are essential parts, is just as valid as the personalities of his normal comrades. It should always be recognised and respected. He should be helped to become himself, not to try to be someone he is not.

As for approach, normal education systems draw on the social nature of children and their inclination to interact with others. They can be relied upon to pay attention to (though not necessarily obey) parents and teachers, follow along with the group, and to imitate one another. From infancy on, interest in other human beings serves as both motivation and medium of learning and development, bringing them into the world of other human beings.

The most fundamental rule in working with autistic children is that *the autistic child does not come to you so you must come to him*. This does not necessarily mean approaching the child and attempting to interact with him. Approaching too aggressively can sometimes have the opposite effect, frightening and inhibiting the child so that he withdraws. It means, rather, coming into his world, understanding how things look to him. It then becomes possible to interact with him in his own way and thereby form a bond with him, and once such a bond is formed, to gently lead him out of himself into the world of others. He then becomes able to expand his world until it connects to theirs.

The autistic child is not necessarily more difficult to teach than the normal child, but his education must be more individualised. At least during the first years of formal education, most autistic children need a tutor to be a liaison to the standard world of the culture in which they live. Among the most important questions the tutor must ask himself is what skills and cognitions the child is currently missing. Which of the things that normal children of his age acquired during infancy and early development is he still lacking? This is important not only for the child who is obviously behind, but also for the precocious child who learns independently and excels his peers in non-standard skills and knowledge.

As the child gradually connects to the culture and becomes familiar with it, and as he catches up on the methods of thinking that he missed during early childhood, this need diminishes. Most intelligent autistic children can eventually manage in a normal classroom without special assistance. Differences in motivation, however, remain and must be addressed. Teachers need to accept those differences and recognise that in spite of normal intelligence, in certain ways this student will always be essentially different from the others.

## 5.2 Early Intervention

It is obviously advantageous to identify autism early because the sooner it is recognised that a child is autistic the sooner it can be addressed. The term “early intervention”, however, is not an appropriate description of the actions taken to help the autistic child. This term is appropriate for the response to conditions such as injuries and infections, that become progressively more severe unless something is done to stop them. Its use is part of the inappropriate application of the medical paradigm to autism due to the erroneous belief that autism is a disease and the goal of therapy is to cure it. But autism is not a disease and does not become more severe. It is a condition that, if not addressed correctly, can result in failure to develop appropriately and can lead to secondary problems. The goal is not to cure an underlying condition or prevent its progression, but to enable the child to develop optimally in consonance with it. It would perhaps be more appropriate to call this “early developmental assistance”.

While the question of specific techniques is clearly too vast to be addressed here, some general principles can be mentioned. Simply providing the child with situations and experiences conducive to his own mode of development is sometimes the most effective approach. Every autistic child needs toys by which he can discover the world. They must be appropriate for his current level of development, difficult enough to be interesting and challenging, but not so difficult that he is unable to do them or cannot even understand what he is supposed to do. Children who do not speak need to be exposed to speech sounds so that they can become familiar

with them and learn about them until they are ready to start producing them themselves. Caregivers should speak to the child and tell him stories while he is playing even if he does not seem to be paying attention. Television and recordings are also extremely valuable, though they cannot take the place of live speech.

Coaxing or forcing a child who does not want to interact is generally ineffective and can even be counterproductive because it intensifies resistance. The sensitive teacher or caregiver knows when and how to use pressure, but when in doubt it is generally better to refrain.

Caregivers need to recognise the ways in which a child is progressing and encourage them. If he shows interest and ability in music, mechanics, or simply in balancing blocks on one another, they should help him continue to improve. At the same time, they should use his current interests to expand his field of interest to include new things. And although neither praise nor encouragement are needed to motivate him, since his own natural interest and enjoyment are more than sufficient motivation, they are nonetheless valuable because they help him form a bond with caregivers and other human beings.

### **5.3 First Goal: Gaining Control over his Own Life**

The overall long-range goal, as we have already said, is that the autistic child learn to get along with other people and become integrated into society. Along side this are two other goals of equal importance, but less specific to autism, for while integration into society comes relatively easily for most children and is only a serious challenge for those who are autistic, these are challenges for all children. The most important and fundamental is to gain *control over his own life*. This is generally referred to as “independence”. The term “independence”, however, is not an accurate description, and is, indeed, misleading. No human being is truly independent. On the contrary, each individual is dependent upon many other individuals and upon society in general. What is really meant is to be able to make one’s own decisions and to control, within the limitations of necessity, one’s own future. The mature adult is independent in that, unlike a child, he no longer needs anyone else to conduct his affairs for him and to organise his life. If an autistic child grows up to be a hermit, lives in the woods and grows his own food, he may have achieved something close to true independence, but that is not at all what we had in mind for him. In helping and guiding the autistic child, our goal is not only to free him from the care and control of others, but to enable him to cooperate with others for their mutual benefit, to be an active participating member of society.

For the autistic child, independence and integration into society are therefore two separate but interrelated goals. Part of independence is learning to be a human being, to be comfortable interacting with other human beings and to be acceptable to them. That, in turn, involves accepting, on the one hand, his own autistic personality, and on the other, that he is nonetheless a human being and that the essential nature of a human being is to be a social creature. So he must learn to be himself, and as himself, to be comfortable in society. Like learning to ride a bicycle, this goal can only be achieved through much effort and a certain amount of pain. He must keep on interacting with other human beings, and in doing so inevitably make mistakes and suffer the consequences. Indeed, like riding a bicycle, the challenge is to maintain balance.

For normal children, a large degree of understanding and control of their lives is gained simply from adoption of socially taught patterns of behaviour. For autistic children this is necessarily weak, so they need to achieve that control by different routes. Awareness and understanding may have to precede behaviour, and gaining control may be a goal rather than a natural outcome. There is no precedent in normal education for the formal instruction that the

autistic child needs in these areas, so it requires the development of new teaching methods as well as new means of evaluation. Sometimes his mentors may be able to help him and save him, but not always. Ultimately, he must do it himself.

#### **5.4 Second Goal: Seeing Order in the World and Acquiring Mental Skills**

Part of being human is making sense of the world. Whether or not an individual has an innate inclination to look for order in things, experience teaches him that it is advantageous. Recognising patterns and order is a kind of intelligence shared only by the highest animals. One who lacks it, even though he is a human organism, is not functioning in a human way.

As we have seen, autism does not, in itself, involve impairment of this aptitude. An individual can be severely autistic yet see order to the same degree as any other intelligent human being. It is only when autism is accompanied by mental handicap that the aptitude to see order is compromised. However, when, because of deficits in social learning, an autistic child does not learn socially-taught ways of organisation, he may fail to actualise his aptitude. He then functions like one who is mentally handicapped even though he has the potential to function normally. Especially those who are mildly mentally impaired generally function at a level below their aptitude due to insufficient social learning. One of the goals of education of autistic children is therefore to assure that, to the extent each individual is capable, he learns *to view the world as having order, to look for that order, and to learn it and use it to guide his conduct.*

Since most autistic children learn best by independent discovery, tasks through which they will learn ordering, arranging and other kinds of reasoning are effective vehicles of learning. While such tasks are important for all children, their importance is relatively greater for autistic children. Of the many social activities by which normal children learn, one that is effective for many autistic children is playing games. Since the rules of games are explicitly stated, they are more easily understood than the subtle rules of life. Games and other ritualised kinds of socialisation therefore serve not only as a step toward increased social interaction but also as a source of cognitive development. Games like draughts help a child think in terms of implications of actions. Card games help him not only to think about implications, but also to become more aware of the difference between what he knows and what others know, thereby contributing to his development of Theory of Mind. Even simple children's games that involve little or no strategy teach the child to order and arrange.

These three goals are tightly interconnected, each contributing to the others. All three are essential developmental goals for all children, not only those who are autistic. The difference is that in autism the ways by which they are acquired are different.

#### **5.5 Practicalities in Teaching Autistic Children - Using the Child's Individual Interests to Motivate Learning**

Teaching an autistic child need not be more difficult than teaching a normal child, as long as the teacher is ready to relinquish standard methods and take advantage of the child's individual qualities instead. Of course, educational systems do not welcome this, since individualised programmes involve much more work than standardised ones, but their success, once implemented correctly, may convince opponents that they are well worth the effort.

In teaching normal children, social interest can serve as a universal motivator. By utilising their natural inclination to attend to others, the skilled teacher can direct them to whatever he wants them to learn. Especially when there is a positive spirit of co-operation between children and teachers, a system of instruction propelled by social interest can be very

powerful. Teachers who are used to working with normal children therefore find it difficult to work with autistic children for whom no comparable universal motivator exists. Reward is a poor substitute, for while social interest motivates the child to participate in the activity itself, reward only motivates him to achieve the goal. Once the goal has been reached and the reward received, both goal and activity lose meaning. Rewards are therefore effective in moulding behaviour, but are of only limited value in stimulating cognitive development and achieving long-term learning. Reprimand and punishment are even less effective. This is not only because autistic children tend to be stubborn but because they may fail to grasp the connection between the punishment and their behaviour, and sometimes even to understand what is expected of them, so punishment is pointless.

The most effective sources of motivation for the autistic child are his own personal interests. Properly channelled and incorporated into an individual programme, they can more than compensate for lack of social interest. We have already explained that limited interests characteristic of autism are not a primary trait but a secondary one, resulting from failure to expand areas of interest the normal way, through social learning. Many autistic children are really very curious and do not hesitate to explore new places and objects. In an environment which is sufficiently rich and varied and in which curiosity is rewarded rather than punished and stifled, they can not only amass world-knowledge, but develop cognitively as well.

The most serious impediment to education is therefore the use of standard methods that are inappropriate for autistic children. Although the autistic child's interests have not aligned themselves with that of the group the way other children's have, they are not alien and inscrutable. They have developed within the same reality in which other human beings live, and with skill and sensitivity the teacher can discover them. Nor is it necessary to devise entirely new activities to exploit them. Of the many activities that have been effective for normal and autistic children in the past, there are nearly always some that will work. And with imagination and creativity, even impractical skills and useless knowledge, such as flicking rubber bands and counting street lights, can be used as a foundation for valuable learning. Even children who are moderately mentally handicapped are capable of considerable achievements if their natural aptitudes and dispositions are utilised correctly.

If an appropriate programme is applied during early school years, the need for individual instruction decreases as the child grows and develops. Not only does he now share a common foundation of knowledge, he has a general, though perhaps still imperfect, understanding of his place in society and what is expected of him. He knows what school is about and how children are supposed to behave. So although individual interests may remain more important than social motivation, he can be integrated into the standard school system.

## **5.6 Beyond Academics - Teaching the Autistic Child Social Skills**

Academic success, however, is not all of life. There are other things that the autistic child needs to learn that are indeed much more important. In their concern about the present, many parents and educators overlook the fact that one day school will be over and the autistic child will have become an adult and have to go out into the world where he will need very different kinds of skills. Beyond specific skills such as knowing how to use public transportation and go to shops, banks and offices, he will need the more subtle skills involved in interacting with other human beings in all sorts of situations. He cannot be expected to learn them on his own the way normal children do, any more than normal children can be expected to learn mathematics on their own. He needs to be taught, and he needs opportunity to practise and perfect them. Even those autistic

children whose intelligence is above average and who do well academically without special assistance may end up deficient in social skills if they do not receive the appropriate training.

Many autistic children present the additional challenge of lack of motivation to acquire social skills. They simply don't care about socially acceptable behaviour, and since they don't consider it important, they don't learn it very well. They feel they are fine just the way they are and see no reason to change to be able to get along better with others. Though it may seem strange to most normal adults, even autistic children who understand what they are supposed to be doing may not appreciate its value. So before they can be effectively taught, they must become convinced that social skills are valuable and are worth the effort to learn, let alone practise.

Perhaps the most valuable assets an autistic child can have on the rough road of social development are patient and compassionate friends and guides. If a child knows his teachers care about him, he will trust them and be ready to accept their advice. Under their guidance, he may adopt socially acceptable behaviour even before he sees its value himself. Trusted guides and advisers are important for the autistic adult as well. Even more so than normal adults, who are guided by society and social convention, the autistic adult needs friends to be his social eyes and ears.

Among the many things an autistic adult needs to learn about society is that there are unwritten laws of social behaviour, and they are often more important than those that are stated explicitly. This is, indeed, but one instance of the broader principle that social appearances do not always reflect reality. Like idioms, whose meaning is not the literal meaning of the words of which they are composed, cultural institutions are not always what they are presented to be. Honesty does not mean always telling the whole truth about everything, and schools serve many purposes other than education.

Though these subtleties are not normally realised until adolescence, since young children are still busy learning the explicit rules, normal children begin picking up pieces of the covert aspects of culture early, so when the time comes, they are ready to put them together. Autistic children, however, not being sufficiently sensitive to cultural subtleties to acquire them on their own, need trusted friends and mentors to enlighten them to the secrets of culture that teachers and other official representatives of society will never reveal.

## **6. Conclusion: The Autistic Adult as a Member of Society**

As the autistic child matures, his share of the burden of accommodation gradually increases. Many eventually become able to assume the entire responsibility themselves and function without assistance among those who neither understand their condition nor care to help. Others will always need some help and support. None, however, cease to be autistic. Fundamental differences remain, essential parts of the personality. Some will always find social interaction stressful. Even though they give the appearance of comfort and ease, it continues to require attention and effort. There are others who learn to interact effortlessly, but never experience the same kind of pleasure from it that normal adults do. And then, there are some who learn to enjoy socialising but still prefer to be by themselves. Each autistic individual needs his own balance of private and social activities, which no one but he himself can determine.

Some autistic adults have a strong desire to overcome behavioural abnormalities and greatly appreciate patient help and guidance. Others accept their limitations and would rather be left alone. Friends and relatives who want to help need to consider how to respond to errors and ineptitudes. The appropriate response varies from situation to situation and from one individual

*Chapter 14 - Autism and Society - 15*

to another. As a rule of thumb, errors that are likely to produce problems in the future should be corrected, while those that are harmless or insignificant may better be ignored.

Autism is a challenge, but not an insurmountable one. The solution lies not in trying to eliminate it but in learning to understand and accept it, and to enable each autistic individual to become integrated into society in his or her own way.