**PARTNERS WITH disABILITY**

**SECTION 3**

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THOUGHTS ON DIGNITY AND RESPECT

It is within the ethos of Kith & Kids to regard each person as an individual with his/her own dignity and to offer each other respect. Therefore dignity and respect need to feature in whatever we do and we expect all participants on Kith & Kids projects to honour that.

In order to achieve some clarity around this guideline these two issues and related issues will be explored in more detail below, the first part of which is a bit like a brainstorm. In other words, it is a jotting down of ideas that may not themselves be a clarification but they may well generate discussion to reach fuller understanding. In short, this is by no means a full exploration, but it may serve to raise awareness and provoke thought.

DIGNITY/RESPECT - What does it mean?

Honouring dignity and giving/receiving respect:
- adds distinction to the state and quality of a person’s life and/or being
- means being worthy of honour
- is an attitude of admiration and/or esteem
- is polite or kind regard, consideration/respect for people’s feelings
- means paying proper attention and paying proper attention to a person

When interacting with each other, try to have an awareness of:
- how you pay regard to yourself and others
- understanding
- empathy
- being judgmental

What do we understand by dignity/respect in our interaction with each other?
- Being thought about, being considered
- Being consulted when it involves us
- Being honest
- Being listened to, being heard
- Sharing
- Making sure understanding is present

Why offer acknowledge dignity and offer respect?
- To receive respect
- To attain equality
- To value and validate
- To attain confidence and support another’s confidence

How does language support dignity/respect?
- The words we use
- The body language we use
- The attention we give - listening, hearing

What happens when you make assumptions?
- Misunderstanding
- Miscommunication
- Placing our own experience on others
How do our feelings control and motivate us?

- **Enthusiasm** - positive motivator, sometimes doesn’t allow us to think
- **Anger** - can propel us to get things done
  can abuse ourselves and others
- **Fear** - can stop us trying things
  can challenge us to do things
- **Joy** - celebrates, allows fun, validates the positive
- **Sadness** - can allow us to feel our own and other’s pain/hurt

There are many other feelings which can support us and others to be in touch and aware.

For some time “choice” has been a bit of a buzz word but we feel it needs exploring if it is not to be an empty slogan.

What do we need to make choices?

- Understand exactly what is being offered
- Understand alternatives
- Understand consequences
- To be informed - uninformed choice is no choice

Labelling/categorising: How does this affect us and others?

- Can lead to misconceptions
- Makes assumptions
- Can help make sense of our lives
- Can be restrictive
- can be liberating

**LANGUAGE**

We should always try to be aware of the level of our language. Our aim is to be understood and to understand. Using long sentences and complicated words may stand in the way of the sharing of experience. The same could be said of using pigeon English or “baby-talk” (“talking down” to people).

It is important to “feel” the level of understanding and language the member has. Try, through the relationship that develops and the confidence that increases, to build on a shared understanding of mutual dignity and respect.

**ASSUMPTIONS**

It is easy to say that we should never make assumptions about another human being - but we all do this, often subconsciously. We can at least try to be aware of the assumptions we make. They will affect the whole way we react, interact, and in turn the way our members interact with us. It will affect how we feel about each other, ourselves and the world around us.

Assumptions are usually based on our past experiences of life, and these may be very different from those of the people whom we are making assumptions about.
By assuming that someone feels sad if we think they look sad, we are not allowing them the dignity to explore and acknowledge their own feeling. They may be deep in thought about their next activity, new coat or feeling cold. You have assumed they are sad. Think about how it would make you feel if someone made these kinds of assumptions about you.

FEELINGS

Probably the most powerful part of our lives that motivates us through all our paths. Our positive and negative experiences will affect the way we feel about ourselves and about others. Our feelings may help to mobilise or immobilise us to achieve our goals in life.

Try to be aware of your feelings and to sense those of the person/s you are with. How do you feel about the way you are relating to your Kith & Kids member and/or your fellow volunteer? Is your attitude/language different from one to the other?

Something else you could think about: Are you supporting and helping to make things happen or are you taking control and making things happen?

LABELS

Like assumptions, we all stick labels onto other people. These can be confusing, hurtful and misleading.

Society refers to “the handicapped” or “the disabled” or other more specific labels.

We refer to people. Their disability is only a part of their whole person. Our members are people first; people with abilities and disabilities; people with feelings; with their own experiences; people who want to share in the doing rather than wanting to have things done for them; people with needs, as we all are.

CHOICE

Much has been written and said about choice and fancy terms are used which often confuse. These mean different things to different people, depending on our past experiences and our aims.

Choice is positive if it is informed choice. Without the understanding of information we cannot have the freedom to choose. In many instances, by giving someone choice, without the knowledge of how to choose and the range of choices available, we are not offering the person freedom of choice.

For example, is it right that a person be allowed to choose whether to wear open toe sandals on a freezing cold day? Some people would say yes.
We need to explain the consequences and support the person to have an understanding of the possible outcome(s) of the choice(s) made. If we do not do this, the freedom of choice is not real.

Think of and discuss other examples of choice and how we use it in our daily lives.

It is important that the choice of where to go, what to do...etc., is made by the student and volunteers together. If the volunteers allow the member to choose all the time where they are all going, what they are all doing, the member does not have the opportunity of the experience of sharing, negotiating, making decisions together and taking responsibility (see also the 4 R’s under Working through Conflicts in SECTION 4).

GENERAL

If you feel you are not understood or do not understand, explain and ask in different ways. Explore other possible ways of communicating: e.g. use the senses: smell food, taste the drink, touch, see... Your enthusiasm and willingness to explore will be evident to our members.

Ask your support person for guidance (i.e. parent, staff, fellow volunteer) in order not to feel isolated. Also, if you can express what you feel and what you want/need, it will assist others to do the same.

We all enjoy doing things for others as well as having things done for us. The same goes for our members. Each, within her/his ability and in spite of any disability. Please remember, the disability is only a part of the whole person.

Disregarding a person devalues. It leaves the person with no control over her/his own life. It leaves her/him feeling powerless. The “Does He Take Sugar” syndrome really does exist in society, but by beginning to see people as individuals first we can try to turn it around.
LET'S COMMUNICATE!

INTRODUCTION

From an early age we develop a use of language to express our ideas, wishes and needs, both orally and written. Perhaps it is less obvious that before we begin to speak as children, we have already cultivated several facial expressions, bodily gestures and oral sounds. These enable us to communicate with the people around us, until we start to speak. As we grow older and become more skilled with the use of language, these other modes of communication tend to take second place.

However, these secondary modes are still present and very much a part of our communication repertoire. Strangely enough, it is when the use of language breaks down, that we often revert to these more primitive forms of communication.

As an example, here is a situation I found myself in:

I was travelling on the tube recently and there was a young man and woman sitting opposite. An elderly man (most definitely the worse for drink) decided to come and sit right next to the couple, even though there were vacant seats around. Before long he tried to start a conversation, but was almost incoherent. After several platitudes, the young man, in no uncertain terms, told the elderly man to take a hike. Of course his reaction was to try to talk to them both even more. They replied with crossed arms and made several sounds of distaste. Seeing that he was being ignored the elderly man touched the young woman’s hand in order to get her attention. She promptly slapped his hand and they both moved to another carriage. I stayed on the tube for a few more stops and could not help but observe the feelings of rejection the elderly man was experiencing. I felt he genuinely just wanted to talk to someone.

This situation illustrated several important points regarding communication.

i) Your ability to communicate effectively is directly proportional to the variety of experiences and situations in which you have needed to express your thoughts. The more you communicate, in whatever form, the better you become at it.

ii) Many people have limited opportunities and environments in which they feel comfortable enough to express themselves orally or physically. By this I mean without the fear of being rejected, misunderstood or even plain ignored. Quite often they have been denied the basic life experiences that are taken for granted in main stream society.

iii) Non-communication is a form of communication. If someone is refusing to talk or physically removes themselves from an environment/situation, they are still communicating their thoughts and feelings.

iv) Society has established acceptable ways of communicating in work and social environments. To some people these environments in themselves can be overwhelming and frightening. This may result in “odd behaviour” which can often be explained with hindsight, and requires patience and understanding.
v) We communicate by thoughts often generated from subconscious feelings and emotions. We need to try to come to terms with our own inner feelings.

vi) If someone is communicating with you in a way that makes you feel uncomfortable, then value that feeling and express how you feel. This should be done with caution and sensitivity.

These ideas have been kept general to highlight an important point concerning the work you have undertaken as a volunteer:

Your ability to communicate with a person who has a learning difficulty is directly related to the communication skills you use consciously or subconsciously everyday.

You have already developed skills of communication through your own life experience. All these can be used when communicating with a person who has any degree of learning difficulty or physical disability. What is even better, is that you are allowed to make mistakes too!

As your relationship with a person with a learning and/or physical disability develops, and you begin to see through the disability, you will realise that s/he is just like any other person. S/he has a personality, wants, dislikes, needs etc. most important of all, as the member you’re supporting gets to know you, s/he will learn about your personality, wants, dislikes, needs etc.

In fact, an ideal to work towards could be to communicate with the member in the same way you would with anyone else. This may mean making slight allowances in some cases, but these are no different to the allowances you make when meeting a colleague at work or at college, or meeting someone who speaks a different language from your own.

Here are some ideas which I hope will enable you to communicate more effectively on that initial meeting. From then onwards remember that you already have the skills required.

**Be natural. Be yourself!**

**Let’s communicate with speech**

Some people with learning difficulties are quite able to express themselves using language. Others rely on one word utterances. Your Kith & Kids member may make sounds to communicate as opposed to spoken language.

Whatever the case, it is worth bearing in mind the effort required by some members to make any sound at all. This is particularly relevant in social situations. It is often not easy to communicate with strangers on a first meeting. For some people the environment they find themselves in, may in itself be overwhelming. Let alone trying to speak. The ideal is to try and create a warm relaxed atmosphere.

One way of doing this is by getting involved in an activity, which releases the pressure for direct conversation. Then as trust is built up, communication barriers can gradually come down. The use of music and singing are great ways of communicating to one
another and for the shedding of inhibitions (though sensitivity will tell you if this is too much for the person you support, or yourself!).

Repetitive questioning may also be encountered. Often the questions will not be relevant to the present conversation. An increase in the number of questions could be a sign that the student feels insecure. Inappropriate questioning may indicate a need for attention and interaction.

Let’s communicate using body language

We all use our bodies to communicate our thoughts, feelings and emotions. Some of the students you encounter may be severely physically disabled. The degree of movement can range from being able to get in and out of a wheelchair to no movement at all. Learning to understand the body language of the member you are supporting will take time, but the key is observation. Someone who is restless in a wheelchair may be saying they need to use the toilet. While a fixed facial grimace could mean that s/he is not comfortable in the wheelchair, or that s/he is hungry.

The member may use their body language to communicate feelings of excitement, pleasure, or vulnerability, insecurity, or even boredom. This can manifest in odd physical behaviour, and may in extreme cases (especially if ignored, or misunderstood), aggression.

A more mobile member may suddenly lie down in the middle of the floor for no apparent reason or start jumping up and down. These are ways in which they may try to communicate how they feel at the time. Within the boundaries of safety and acceptability, these kinds of “challenging behaviour” should be respected as a genuine form of self expression and communication. There are no set right or wrong ways of dealing with such situations, due to the fact that each situation is always unique. The same environment with different people will cause a different response and vice versa. Perhaps one way is to try to see the world as seen through the eyes of that person, and ask if you can come into that world (ie if the member lies down in the middle of the floor, ask if you may join her/him, and share that experience).

Let’s communicate with touch

Touch can be a beautiful way to communicate. Touch can be used to give reassurance, to show camaraderie and create positive feelings of warmth and security. The person you support may enjoy communicating by touch, and may only be able to communicate in this way. On the other hand, a person may feel uncomfortable or even frightened when touched. It is up to you to identify the member’s boundaries, and let it be known what your own boundaries are.
Massage is an ideal way to melt barriers, if the person is willing. It is an activity that everyone can get involved in, even with little or no experience. It is extra beneficial to those members who use wheelchairs to help circulation, and those who are excitable and energetic as a way of relaxing.

Let’s communicate creatively

There are many different forms of communication aids: these range from British Sign Language, Makaton (modified BSL for those with learning disabilities), Bliss boards, computerised communicators, card systems. Whichever form of communication your member is using, your approach will be the same. Even if we do not speak the same language, our tone of voice and body language convey a message of wanting to get to know someone - think about when you have met someone who speaks a different language. There is always a way to learn each others language if we are patient and creative.

Let’s communicate as a team

The parents of the people you are working with will have an in-depth knowledge of their son’s/daughter’s communication skills. Do not be afraid to ask about anything you are unsure of. They are fully aware of the sounds, gestures and expressions (eg basic sign language) their child makes to communicate their thoughts, likes, dislikes and needs.

Finally, remember that you are human and may encounter stressful situations. Do not keep it inside but take time to talk to someone about how you are feeling. We all make mistakes. If someone tells you otherwise they are either lying or you have just communicated with the Child of the Creator. In which case I cannot think of anyone better to COMMUNICATE! with.
AUTISM

Introduction

Like the term ‘learning disability’ autism is rather an umbrella term. In Kith & Kids, there are many members who come under the label of autism, or autistic spectrum disorder (ASD).

The label can be a real hindrance when people expect it to mean one thing, when in fact the personalities, abilities and disabilities of our various members with autism differ and range tremendously from one person to the next.

Rather than trying to generalise about autism we refer to The Guardian article which, with their kind permission, has been included in this book. We feel this provides a very good introduction to finding out more about autism.

The illustrations below show just a few of the many ways in which autism may be displayed. What we would like you to bear in mind above all when you find yourself supporting someone who has autism, is that you try to get to know the person. Only through getting to know the person will you find out how their autism affects them and how you can best support them.
Some experts call it mind blindness. Others suspect that it’s caused by a paralysing terror of life. But they’re all agreed on one thing - it is one of the most mysterious disabilities known to science. So when a young Berliner began to write messages from the closed world of autism, it felt like a miracle. And then the doubts began.

There is a particular kind of story which seems designed to tease newspaper readers. It is tiny - often just a single paragraph - and it frequently concerns cancer. You stumble upon it by chance, at the foot of a page deep inside the paper. Typically, it tells you that “scientists have discovered a chemical in the saliva of moths which inhibits the growth of tumours ....” Against your better judgment, you offer up silent thanks. We have all crossed another bridge, you say. Humanity has jumped forward a square. But even before the page is turned, a wise old voice whispers at the back of your mind. Should you live to be a thousand, it says, you will never hear another word about moth saliva. And so it is with Birger Sellin.

Birger’s book has just arrived here, having sold 50,000 copies in Germany. It comprises a selection of short passages and poems by the young Berliner, who began writing at the age of 17. Birger’s work would not be out of place in a modern-day book of psalms, and the collection’s title, translated as In Dark Hours I Find My Way, seems to reflect this. But the nature of Birger’s writing he puts a lump in your throat which is quite hard to swallow is almost beside the point. Rather it is its very existence which invites rejoicing. For Birger is severely autistic.

The book’s subtitle - Messages From An Autistic Mind - hints at the significance of this. For Birger’s writings do indeed appear to be communiques from a country whose borders have been sealed against all outsiders. As such they offer an insight not merely into the mind of the author, but into the nature of a riddle which persists in evading solution. One sentence on the book’s jacket goes even further. “Autism,” it says, “is one of the most mysterious disabilities known to medical science.”

Is there a case for elevating autism to such an awe-inspiring status.” Leaving aside for a moment the significance or otherwise of Birger Sellin’s contribution, scepticism would be understandable. After all, isn’t medical science adrift in a sea of mysteries? Smash your leg and a surgeon can fix it. But go down with a virus and you are on your own. From depression to PMT, and from asthma to backache, it’s the same story. Medicine, it seems, is still a little short on answers. So what sets autism apart? Simply this. After half a century of seeking an answer, the world’s experts have barely worked out the question.

The problem has been partly one of definition. Before anyone could hope to prevent or cure autism, they had to find out what causes it. And this is considerably more difficult if no-one can even agree which of their many and varied patients suffers from it and which does not. For autism covers a multitude of sins.

Its public image is a shambles. Star of the show is Dustin Hoffman, whose faultless portrayal of an autistic adult in the film Rain Man at least dispelled the rumour that this condition was for children only. And while the Hoffman character had little understanding of the world beyond his own obsessive routines, his disability did have its positive features. The man was what used to be called an “idiot savant”, though the term has now been supplanted by the more sensitive “autistic savant”. He could memorise whole telephone directories. He could perform impossible feats of mental arithmetic. And fortunately for the plot, he could calculate the odds at Vegas.
Closely behind the Rain Man comes Stephen Wiltshire. The south London boy who rattles off detailed sketches of complicated buildings having given them the briefest of sidelong glances, is a true ambassador for autism, and his books of drawings are bestsellers. As we turn the pages and follow his strange career (Stephen has now revealed musical abilities, and apparently plays the piano like a natural), we note with a shiver that, in his otherwise faithful rendering of the old Midland Grand Hotel facade at St Pancras Station, Stephen has drawn the clock face in mirror image.

But in the backs of our minds, there is another picture of autism - one which seems irreconcilable with those first two. It is the incontinent child who sits on the floor - who rocks to and fro - who bangs his head on the wall and bites his own arm till it bleeds. Unable to make sense of the outward world - confused, even, as to where he ends and that other world begins - he refuses to speak or make any human contact, either by eye or by touch. He is neither a genius draughtsman nor a human calculator. His condition has been compared to that of a concentration camp inmate whose terror and incomprehension have made him insane, and whose fear of the absolute unpredictability of life and of death has driven him deep into himself. This too, is autism.

Until recently, the public’s confusion has been shared by the medical profession. Not surprisingly, few could agree which package of symptoms was likely to have a common root - let alone what that root might be. The problem is the length of the chain of cause and effect - from invisible brain malfunction to highly visible and variable behavioural disorder. But let’s forget about brains for a moment - they are notoriously hard to fathom. Let’s think about feet instead.

Imagine a world in which medical science has never come across broken bones. Now imagine that you, for your sins, are a general practitioner. Dozens of your patients have fractured a small bone in one of their feet (it sounds silly, but play the game for a minute). You, of course, have no idea what their problem is. How are you ever going to get to the root of it when all you see is a parade of people with a variety of mysterious symptoms?

Some merely suffer slight pain, while others walk with varying degrees of difficulty or not at all. Among these are people whose awkward gait has given rise to serious back and neck disorders. “My spine is in agony,” they say. And in desperation you examine each vertebra for a clue. At the far end of the scale are patients who have never walked at all. Their leg muscles have completely wasted, and on the face of it, this is the cause of their immobility. And as if all this were not confusing enough, many of your patients damaged their feet in accidents which left them with other injuries too. Many of these injuries are crippling, so that neither you nor they even suspect that their feet are damaged.

The first breakthrough comes when you recognise that a number of your patients have something in common. And so it was with autism. Sure, there have always been autistic people, and they exist in all societies. Those familiar with the symptoms can spot the syndrome in Indian folk tales and the traditions of Old Russia. The story of a Maltese boy who arrived in church dragging a cottage door because his mother had said “pull the door behind you if you come to mass”. Probably refers to the literal-mindedness of autistic people. And yet it was not until the early Forties that two physicians, Leo Kanner and Hans Asperger, formally identified the condition.

Working quite independently, each came up with the same word to describe what they were seeing in many of the strange and self-absorbed children they examined. Kanner called it autism, from the Greek “autos” meaning self. And so, by coincidence, did Asperger. Autism - so good they named it twice.
And after the naming came the sorting and the counting. Flip back to your imaginary patients. Some limp because their knees hurt and others because their hips are damaged. Only a few limp because they have broken bones in their feet. Similarly with those who can’t walk at all - sometimes it’s the feet, but sometimes it isn’t. And it’s the same with the back sufferers, and the people with damaged necks. Sometimes the feet are to blame, but sometimes the cause is something entirely different. And if you, their doctor, are ever going to catch on to those little broken bones, you must first decide whose symptoms have the common cause.

Most researchers have finally agreed on how to tell the autistic people apart from the rest. Three areas of impairment have been identified, and for someone to be classified as autistic, they must display all three. First they must have difficulty relating to other people in a normal way. Next, they must have problems with communication. Finally, their powers of imagination must be impaired. Sure they can have additional traits - indeed they frequently do. Obsessive, stereotyped behaviour is one, and resistance to change is another. But the “triad” of core impairments must all be there. Two out of three won’t do.

Once that was agreed, the counting could begin. One study, carried out in south London in 1979, suggested that 22 children in every 10,000 fitted into the broadest definition of autism.

And so it begins. It may be that a method has been discovered of ascertaining who the autistic people are. But the task now is to understand why they are. How do you set about narrowing down the evidence? One way has been to move progressively back from the obvious, up-front symptoms to find some common denominator. We’re not talking about the cause here, but some basic impairment that might go a little way towards explaining the other more varied problems. In the case of our imaginary scenario, such a common denominator might be foot pain. The pain makes some people walk with a limp. It prevents others from walking at all. The pain is not the cause of the problem. That, of course, remains a mystery. But it is a vital link in the chain.

With autism, there is now widespread support for a notion of “mind blindness”. Autistic people, according to this hypothesis, are unable to grasp that other people have minds which exist independently. Researchers have developed ingenious ways of testing the theory, and of screening young children for this extraordinary impairment. One of the most simple methods, the “Sally-Ann task”, uses two dolls called Sally and Ann. Sally has a basket and Ann has a box. There is one other prop - a marble. This is how the test goes.

The child watches as Sally puts the marble into her basket. Sally then leaves and while she is gone, Ann takes the marble out of Sally’s basket and puts it into her own box. Sally then returns, and the child is asked: “Where will Sally look for her marble?” Typically, an autistic child will reply: “In the box.” Most Down’s Syndrome children get it right - as do children with no impairment. By using tests such as this, researchers are able to sharpen their understanding of autism, while at the same time gaining valuable insights into the development of the normal mind.

In the struggle to pin down the processes involved, the tests become relentlessly more sophisticated and the controls ever more rigorous. One problem is that as many as three-quarters of autistic people also suffer from learning difficulties. They may have hearing and visual impairments too, or they may have, say, Down’s Syndrome. As with the imaginary patients who damaged their feet in serious accidents and therefore have other injuries too, autism is most often just one impairment among many.

And the root cause? Back in the early days, it seemed that the whole thing might be rather simple. So many of the children affected had middle-class backgrounds and clever parents. Never mind the fact that these were the people most likely to have their children referred for
specialist assessment - the cause of autism was obvious. It was the parents. More specifically, it was those cold, intellectual mothers - “refrigerator mothers” - who went around all day with their noses stuck in books and their heads full of nonsense. No wonder these children were strange and unresponsive, went the argument. They were suffering from emotional deprivation. And so a generation of parents, already grieving what effectively amounted to the loss of a child, were made to suffer the further agony of guilt.

Today, in Britain at any rate, the “refrigerator mothers” explanation has been all but consigned to the pedal bin. Almost everyone working in the field now believes that physical problems affecting those parts of the brain that process language and information received from the senses are the root cause of autism. Such damage might occur before, during or after birth. Along with as yet unidentified genetic factors, causes might include lack of oxygen at birth, maternal rubella and complications arising from childhood illnesses. There might be an imbalance in certain brain chemicals. Then again, there might not. And to cap it all, it is possible - even likely - that a number of these different factors might be to blame. Not just broken homes, but tight shoes and ingrowing nails too.

And then there’s the maleness thing. Right back in the early days, it was noted that autism affected more boys than girls. Considerably more. The ratio seems to be in the region of 3:1, which is higher than can be explained by any mechanism involving genes. This in itself might suggest a line of investigation. But it is only half the story. So many of autism’s manifestations - obsessiveness, a facility with rote learning an inability to see the wood for the trees - echo types of behaviour with which we are all familiar in the certain type of “normal” male. Man the collector-gatherer, be he train-spotter, football know-all or classifier of Egyptian funerary ware, has much in common with the autistic person, sometimes right down to the social impairment. Asperger himself surmised that autism might be an extreme or exaggerated form of maleness. It is an observation which may yet bear fruit.

The conclusion must be that, if autism is not “one of the most mysterious disabilities known to medical science”, then it is hard to imagine what is. Now what of Berger Sellin? Does his book help us solve the riddle?

Medical science has long had access to the minds of what are called “high functioning” autistic people. While impaired in all the classic ways, these individuals are frequently able to perform well at school, receive a university education and take a job. Their particular grade of disability even has a name of its own (some indeed argue that it is a separate condition). It is called Asperger’s Syndrome, because a high proportion of Hans Asperger’s original patients were of this type.

The Australian-born woman Donna Williams has Asperger’s Syndrome, and she has written two books about her life. In the first, Nobody Nowhere, Donna describes her childhood and her early impressions of a terrifying, splintered world. It is a shocking account, full of noise and fragmented images, and of debilitating mental and emotional blocks. “I’d had trouble with words,” she explains, “but this wasn’t due to disordered thinking and I never jumbled them up like a tossed salad. I either spoke them as emotionlessly mimicked repetitions of what other people had said, spoke with a strange accent, stuttered or found myself unable mentally to form the words to speak at all. All of these problems were due to a feeling of fear of the overwhelming intensity of my very untouched emotions. “With professional help, Donna learned how non-autistic people respond to their environment. Her second book, Somebody Somewhere, charts the laborious process by which she forced herself to renounce the comfort of isolation and accept a new but frightening version of reality.
A comparable picture is painted by an American woman called Temple Grandin. In his book, An Anthropologist On Mars, the neurologist Oliver Sacks describes a meeting with her. The encounter leads Sacks to ponder at length on the nature of the autistic mind and the extent to which it differs from the norm. Temple is herself interested in psychology - and in particular the behaviour of animals. She has become a successful designer of equipment and systems for the humane and sympathetic management of livestock on farms, and has published a book called Beef Cattle Behaviours, Handling, And Facilities Design. She described to Sacks how she had learned to cope with aspects of human behaviour which she, as an autistic person, found baffling. She had observed people’s reactions in different situations, and compiled a mental video library of these. Explaining how other people’s emotional responses puzzled her, she handed Sacks the title for his book “Much of the time,” she told him, “I feel like an anthropologist on Mars.”

Birger Sellin is different. He does not suffer from Asperger’s Syndrome, but from a degree of autism which should rule out any ability to introspect or report. On the face of it, therefore, his “messages” are astounding and of a different order of significance.

Birger was born in February 1973 to Annemarie Sellin, an RE teacher, and Dankward Sellin, a law student. He was a normal, happy baby. He was also an early talker. But at the end of 1974, his parents lost him. Not literally, of course, but to most intents and purposes. It began on Birger’s first day at nursery school. He wouldn’t stop screaming when his parents picked him up at midday, and it was the same the next day too. Soon he developed a recurrent ear infection, and by the time it had cleared up three months later, Birger had ceased to be the same child.

He became terrified of other children. His language deteriorated, then dried up altogether. He began to avoid eye contact and stopped responding to his parents. Before long, he was spending most of his time under the dining room table. His favourite pastime was running glass marbles through his fingers. And his only utterances were screams.

In 1990, Birger’s parents heard of something called “facilitated communication”. Developed in the late Seventies by an Australian teacher called Rosemary Crossley, and much debated in the United States where it became popular for a time, it was a technique which, it was claimed, enabled and encouraged people with cerebral palsy and autism to “speak” to the outside world by way of a keyboard. A keyboard and a helping hand. Initially, the “facilitation” would involve a trusted person - in Birger’s case, his mother - supporting the subject’s forearm so that an index finger hovered over the keys. As self-confidence and strength grew, so the facilitator might gradually withdraw, until the support consisted only of a hand resting on the subject’s shoulder.

In Birger’s case, the results looked spectacular. “It was like tapping a sudden spring of water,” says his mother. In Dark Hours I Find My way presents a selection of his tappings, assembled in chronological order so that the reader can follow his development from strings of letters and single words to whole poems a couple of years later. Birger was not Stephen Wiltshire, and nor was he the Rain Man. By his late teens, he had been written off as incurably insane. He had been mute for 15 years. Yet after a couple of months at the keyboard, he “told” his mother on the computer screen one evening: “i dont i want to stop i love youyes”.

Two months later, Birger, who uses no punctuation and likewise dispenses with capital letters, was apparently offering insights into his state of mind. “you mustn scold but today you were very patient,” his finger typed. “i dont fit into the widde world atall because im afraid im just afraid of ordinary things that seem as halla harmless as buildings well they seem threatening to me im always scared but today it was specially bad  becc be cause you shouted at me .....”
He “revealed” that, from the age of five, he had actually been reading all the books that his parents thought he was repetitively toying with. As his ability to describe and comment on his own condition apparently grew, so Birger seemed to write on behalf of autistic people everywhere (he would pass the Sally-Ann task with flying colours). “How come everyone thinks I am impatient,” he asked one day. “A person without speech has to be so patient there can hardly be any internal equilibrium.” Later he explained “the autistic view of life is like a ship sinking and making nonsense to keep from noticing I am captain of this ship…..” He speaks of “our senseless underworld”, refers to “the enlightened people of the world above” and tells his favourite therapist: “one of the main contradictions in us is our excessively sharp perception of internal structures and our hesitance in getting along with calculable uncontrollable indirect reality.”

Does this not have all the hallmarks of a tremendous breakthrough? If not the moth saliva that prevents cancer, is it not at least the equivalent of one of your own mysteriously crippled patients suddenly announcing that his problems began the day he missed his footing on the stairs - and that, what’s more, he clearly remembers hearing something go “crack!” inside his shoe? Alas, no. There are two reasons why Birger’s writing, extraordinary though it is, takes us no nearer to solving the riddle of autism.

First, and perhaps most obvious, is the question of the method used - facilitated communication. In a review of the English edition of Birger’s book, the scientist Uta Frith, who translated the work of Hans Asperger and has herself made a major contribution to the study of both autism and dyslexia, speaks wearily of “this latest craze”. Cases of facilitated communication, she says, “have been rigorously tested and proved illusory.” She would find it easier to believe that Birger’s writing is produced through a gifted psychic medium than the actual claim that is made. While she is convinced that there has been no intention to deceive, she firmly believes that Birger’s psalms derive, however indirectly, from the light touch of his mother.

In America, where the technique was widely adopted for a time in the early Nineties, there has been a bitter debate among mental health workers, teachers and the parents of autistic children. One critic has called facilitated communication “the cold fusion of special education”, and psychologist Eric Schopler, one of America’s most respected experts on autism, has described it as “the most reckless, irresponsible use of a technique that I’ve seen in 30 years in this field”. Chief among its proponents has been Syracuse University special education professor Douglas Biklen, who introduced the technique in the US. Her argues that facilitated communication does work, but that its results simply cannot be measured using traditional techniques, which often frighten the subjects.

In 1992, staff at the OD Heck Developmental Center for the profoundly autistic in Schenectady, NY, set out to prove that FC did work. The concocted an experiment which involved the use of pictures which were shown either to an autistic subject or their facilitator, and sometimes to both. The results of 180 trials were devastating. They showed that the facilitators were doing the communicating, albeit unconsciously. More studies the following year confirmed that verdict.

Today, facilitated communication has lost much of its support in the US, and many schools have even banned the technique. Whatever the truth about Birger’s writing, the fact is that his book is fatally flawed in the eyes of too many of the people investigating autism. But even if this were not so, how useful would it really be?

Even such articulate insights as are given us by Donna Williams and Temple Grandin are treated with caution by those digging for the roots of their condition. The reason for this is really self-evident. Given the very nature of autism, the perceptions of those who suffer from it are likely to be skewed - and skewed in ways which outsiders are not yet able to understand or predict. In short, messages from the autistic mind are transmitted on suspect equipment. And since the
nature of the fault is unknown, the messages, while important and revealing in many ways, are unlikely to tell us what they appear to.

Something like one in 10 autistic children are thought to have “savant” abilities - outstanding skills in certain limited areas, such as Stephen Wiltshire’s drawing, or the ability to commit huge quantities of information to memory. A familiar “party trick” (it is, of course, nothing of the kind) is to tell strangers which day of the week they were born on, simply on being told their date of birth. This feat might be performed by a 10-year-old, who is nevertheless incapable of adding up five and five. “Why,” you might ask such a child, “are you able to perform a task which would be beyond most people when you are unable to do a simple sum?” The child may offer an answer. But how useful will his explanation be? The same argument applied to autobiography suggests that its value should not be overrated.

Michael Sell lives in Ealing, west London. Despite being five yours old, he attends school for only two mornings a week. In 1992, a paediatrician at the local hospital said that Michael was probably autistic. Not severely autistic - but he most likely had learning difficulties too. Michael’s parents think he should go to a local authority special school that takes many autistic children. But that school does not yet have enough staff to cope with the increasing number of children in Ealing who are being diagnosed as having autism.

For the time being, then, Michael attends an ordinary primary school, where he is taught in a single, open-plan classroom along with 120 other children. Outside the classroom, being work is in progress. An assistant sits with him while he is there. But because an assistant cannot be found to work with Michael for more than a few hours each week, he only goes in on Monday and Tuesday mornings. Michael’s head-mistress expressed her concerns to the council. She wrote: “That the borough is readily placing a child with such acute special needs in this environment leaves me quite frankly aghast and indeed ashamed.” When the headteacher of the neighbouring special school paid a visit to Michael’s classroom in January, she too was appalled. “It is impossible for Michael to access any learning within such a situation,” she wrote to the council. “It is potentially a very frightening environment for him.”

Michael’s parents also find the situation frightening. His father, Patrick, describes it as “scandalous, insane and Kafkaesque”. Ealing Council says it currently has a backlog of special needs cases to assess. But it does not comment on individual cases.

Just up the road, in Southall, Sarah Middleton manages a residential home for six autistic adults. The home is run by the National Autistic Society, a charity set up in 1962 by the parents of autistic children who felt more needed to be done for people with the disability than was being done by the state. The society now has a number of such homes, as well as schools and day centres. It encourages research, provides training for professionals and advice for parents, and it supports a diagnostic centre where parents from all over Britain can take their children.

Sarah and her staff see themselves as supporting rather than caring for their residents, providing them with routine and a structure that they can understand. She also knows that these are the lucky ones, and that for too many other autistic adults, schooldays will be followed by care in a community that has too much else on its mind. As she talks, Martin paces backwards and forwards, a worried look on his face. He seems like a man who knows he must do something urgently, but can’t for the life of him remember what it is.

Ken comes into the room. Sarah persuades him to show us his weight-lifting equipment and his train-set, which he does in silence. Before we leave him to his weights, he gazes into the box of model carriages. “Network SouthEast,” he says, but to nobody in particular.
Sarah talks about the other residents - Bella, who has a fixation with Steffi Graf, blaming the tennis player for everything that goes wrong in her own life, and Eddie, who will not wear new clothes but goes upstairs five times in an afternoon and changes back into his old ones. And she talks about herself - eight years working with handicapped people and feeling increasingly frustrated and cynical about the enforced dependence on charity.

“As long as we shake tins,” she says, “the Government can leave us to get on with it. And, meanwhile, people just shut off to disability.” She talks of the need to maintain the respect of dignity of handicapped people. “Any one of us could be brain damaged tomorrow.”

The uncertainty which engulfs Michael Sell and his family, the attitudes which Sarah Middleton sees all around her - these too may be read as communiques, stark snapshots from the real world of autism where dignity is the rarest commodity. And there is a further danger, which is that the same uncertainty and the same attitudes speak with equal clarity in the reverse direction. In short, that they function as messages to the autistic mind - from Birger Sellin’s “enlightened people of the world above”.

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BREAKING DOWN SKILLS

When volunteers read the title “breaking down skills” as one of the workshops on a training day, they could be forgiven for their imagination running wild:
Is this about how best to burst into tears? Achieving a graceful collapse? No folks, it ain’t. Is it about coping when you do break down? No, neither. Although an important and relevant issue when you do work so closely and intensively together with other people it is not addressed in this workshop (it is in other workshops).
This workshop is about looking at specific skills, analysing what is involved in them and finding an appropriate sequence in which to share the skills you have with our members.

If you look closely at what may appear to be a simple straightforward skill such as tying your shoe-laces, you will find that in fact this one skill involves a whole range of skills. You would have to be able to reach down to your shoes, to hold a lace in each hand, to manipulate the laces to cross each other, to fold one lace underneath the other, to pull the laces tight, to make a bow out of a straight piece of string, to make sure you hold the bow tight with one hand while the other is doing something completely different...etc. It requires a tremendous amount of co-ordination and dexterity. Where do you start? How do you teach? By physically helping someone, by showing, by talking it through? All of these? Go with your instincts and keep checking with the person you are supporting how they want to be shown, supported or told. If you are making it too simple, they will let you know. If you are going too fast, they will tell you.

Don’t be afraid to share your own uncertainties. For instance, if you are not sure how fast, slow, in which order...etc, just let the person know you haven’t really thought about it all that much before, or you are not sure what is the best way but that you are willing to try a number of ways and they can tell you what suits them best. By sharing your own uncertainties and giving an indication you realise it isn’t so straightforward as you thought at first, you share a sense of fallibility and that it is okay to make mistakes. You are just trying something out together, some of it may work and some of it may not - but that’s okay; through trying together you will find a way that does work.

Apart from being aware of the various stages in learning/teaching a skill, there is also the matter of motivation. It is much easier to try to learn a skill when you feel motivated to do so. Motivation can be enhanced because there is a clear and/or immediate reason for doing something. In other words, there are fun ways of doing something as well as boring ways, there are appropriate times for trying a new skill and inappropriate ones.
If the skill someone wants to learn is making a cup of tea, don’t do it for the sake of doing it, i.e. when nobody actually wants a cup of tea. Do it when you do feel thirsty and fancy a cuppa.

If somebody wants to learn to use the phone but finds it hard, concentrating entirely on the phone itself and the numbers displayed may become frustrating. It could be more fun if there is someone the person actually would like to talk to who is on the other end of a telephone, or when you have a real reason to use the phone (e.g. you may want to find out what time the film starts you fancy seeing), or when a telephone call is part of another activity (e.g. in a drama workshop there could be the need to make a phone call, or in a music workshops the sounds touch phones dials make could be used to remember one’s own phone number...etc).
Another bonus of breaking down skills in addition to imparting (stages of) a skill is that you can see the achievements for what they are. In one week a person may not be able to learn the entire tea making process, but they may have developed an awareness that the water needs to be boiled first and that you use a kettle to do that. The whole skill of making a cup of tea may not have been acquired in one project but parts of it that can be built upon have been learnt and that is a real achievement - don’t underestimate it.

Be creative but please don’t think you have to come up with all the answers yourself. Kith & Kids staff, creative therapists and workshop leaders can help you with finding different ways of imparting/learning skills - talk to them, that’s what they are there for.

When you go home after this workshop try to break down a couple of skills you come across this week - whether it is getting from A to B on public transport, feeding yourself with a spoon, spreading butter onto a slice of bread, or...whatever. Look at the various skills involved and the sequence in which things (can) happen. How did you learn the skill - do you remember? How would you go about teaching it to someone else? It is a useful exercise to try in the run up to the project and it will give you a sense (hopefully) of both how complicated and how enjoyable it can be to learn skills together. For in the teaching and thinking about it you will find you are developing your own skills too. Enjoy!
SUPPORTING PEOPLE WITH A PHYSICAL DISABILITY

Introduction

In supporting a person who has a physical disability you will need some practical skills, such as how to lift someone without doing yourself an injury, how to feed someone, how to help with personal care, how to manouevre and operate a wheelchair...etc. These skills are extremely important but they are not all there is to supporting a person who has a physical disability. You also need an awareness of issues and aspects of support that are possibly less obvious. To get you thinking about these: just think back to any occasions where you have observed or come into contact with a person who was a wheelchair user (or in other words, a person whose disability is clearly visible). Can you recall your reactions?

* Did you avoid eye contact?
* Did you offer a quick smile and turn away? Did you feel al little embarrassed?
* Did you ever speak directly to a person using a wheelchair?
* Did you ever speak to someone who was pushing a wheelchair? And if so, do you remember where you were standing or sitting? E.g. were you both behind the person in the wheelchair, were you standing on either side of that person? Was the person in the wheelchair in any way involved in the conversation?

Whatever your answers to any of these questions, you are not being judged. All we want to do is make you think about certain issues and offer some suggestions for valuing and safe ways (for yourself and the person with a physical disability) of offering the necessary support.

Transferring someone from their chair to floor, toilet etc.

* First, think through all the stages you will go through, be clear about what you are going to do before toiletting. Make sure you have someone to help.

* If you think you may need help, ask someone before you start, don’t try to be heroic and do it all on your own; you may end up hurting both yourself and the disabled person you are working with.

Get to know the wheelchair as well as the person

* There are a wide variety of chairs and attachments. Do the footplates swing round or detach; do the arm rests come off to make transfer easier; is there a detachable headrest; does the chair back fold down to make lifting easier? Also familiarise yourself with any cushions and wedges on the chair, they are there for a reason and will need to be repositioned when the disabled person gets back into their chair.
* Before doing anything else make sure you have positioned the wheelchair appropriately, are, are you next to the toilet for the transfer; is the toilet seat raised, etc? If you are changing someone, do have have a clean nappy or pad and something to wash them with close by? If the person is going to lie on the floor, is a mat in position before you begin?
Make sure they are safe and secure; do not go off and leave them on their own, if there is a problem, call for help.

* If you lay a disabled person on a mat, make sure they are comfortable and not lying on one limb, is their head supported? Check whether they must be laid on their side in case of an epileptic seizure. Take time to ensure that someone is arranged into a comfortable position, think about what you would find comfortable.

* Always apply the brakes on the wheelchair

* Does the disabled person have a waist strap or other belt?
If so, undo this last of all and never leave the person unstrapped whilst you go off to get something you have forgotten. It may be important for some disabled people i.e., if they have athetoid cerebral palsy, to use your hand on their shoulder etc, to make sure they do not fall forwards when their belt is undone.

* Always talk to the person you are working with, tell them what you are doing, and what you are going to do before you do it. This is very important even if they are not able to respond verbally.

* Each person is an individual and may need to be lifted differently, find out if they can weight-bear or if you will have to lift them bodily. Find out if it’s best to do this with two people, and should one take arms another take legs etc, or is it best to support the person with one volunteer on each side?

* If you are new to supporting someone to toileting, changing pads, lifting...you may feel somewhat uneasy or clumsy in doing this. It may help the person you support and yourself if you talk about this. E.g. “I haven’t got much experience with this so it may take a little longer than usual, please bear with me, I will get the hang of this eventually”, or, “Let me know if I’m doing something you feel uncomfortable with, I’m fairly new to this and I feel a little uncertain as to how best to do this”...etc.
Voicing your own doubts and insecurities can be very reassuring because both of you will then be clear about what’s going on. Don’t get too hung up about being slow or a little clumsy, as long as you talk with one another, this is overcome-able.

* All the above also apply for getting someone back into a wheelchair.

**Going out**

Think about and discuss appropriate clothing and as you assist in putting on or taking off coats etc, talk through what you are doing. Use brakes when you stop and then come round and talk face to face with the disabled person. Don’t mess about with the chair i.e., riding on the back, tipping the person up. It may be frightening to the disabled person and also the chair is their only means of mobility. Pavements: don’t push the chair off a high pavement, use the foot bars to tip the chair, if necessary take the person down backwards from a high pavement; don’t rush, look for dropped kerbs.

**Feeding**

Find out the disabled person’s feeding needs, i.e. do they need to have food mashed? Any cultural food requirements? How much can they do for themselves, do they need special equipment such as a feeding cup, non-metal cutlery? Does the disabled person need to use a bib, apron or napkin? Talk to the person while you feeding them, tell them what you are doing. Don’t rush, take your time and be calm. Eating may have been stressful for the person in the past. Try to gauge the size of mouthfuls the person can take as you get to know them - it’s very frustrating to be fed one baked bean at the time! If the person doesn’t need to have their food mashed, don’t. If there are several portions on the plate take a bit from each for each mouthful, think about how you eat and apply this to feeding (unless you have terrible table habits!!). If necessary, wipe the person’s mouth as you go along, don’t leave it till the end of the meal.

**Dressing/Undressing**

Think about what you are doing, does the person have one arm which has more movement than the other? Put shirts, jacket arm etc onto the less flexible arm first. Adjust clothes over shoulders to allow more movement. Would it be easier if the person was out of their chair on a mat or changing table? Roll the person over to pull up trousers etc, try not to pull them around unnecessarily. Again, talk to the person, tell them what you are doing and going to do.

**Communication**

As said, always talk to the person you are working with. But be aware of how you are doing this. If the person you are supporting is using a wheelchair and you are standing, your head will be well above theirs. It may be uncomfortable for that person to have to look up all the time, it can also feel a little intimidating if you are literally talking down to them because you are up there and they are down here. If at all possible try to be on the same level (in terms of physical height) as the person you are supporting; try to make eye contact easy because it is a very important way of communicating - a simple way would be to pull up a chair and discuss things while both of you are seated.
If you want to talk something through with your fellow volunteer, try to make sure that you are not (literally) talking over someone’s head. Can you imagine what that would be like for the wheelchair user? It maybe something like trying to watch a tennis match that’s being played over your head. Also try to avoid both volunteers standing behind the person. How is the person to know what’s going on if neither of you can be seen?

Do not assume because a person’s disability is clearly visible that they cannot hear you (no need to raise your voice) or are unable to say what they want, or unable to understand your questions. If you have a question concerning the disabled person, ask them first. If you are unclear about their reply, ask in a different way or ask a person who knows them well but in doing so make sure you include the disabled person. You can include someone with a look or with the way you ask the question even if the answer comes from another person.

We all want to be able to have a say in things that affect us directly and we all want to feel included; for people who have a disability this is no different. No one, but no one, is immune to or unaware of being left out. In Kith & Kids we strive to ensure that no one feels left out, that everyone is heard.
Some members of Kith & Kids are blind or partially sighted, and in our training days, we explore the important issues and points which will help volunteers to support those members. Here are some reminders of those points:

* Ask the member and/or his/her family, what is most helpful, and do it.
* Don’t worry about using sighted language - it’s fine to say “look”, “see” and so on. The member does both those things, just in a different way to those who do it with their eyes.
* When guiding the member, mention “step up/down” etc., and describe your surroundings.
* Describe visual information in group activities.
* Encourage others to introduce themselves by name.
SOME PRACTICAL POINTS ON DEAFNESS

Kith & Kids members have a variety of physical and/or learning disabilities, and some have varying levels of hearing loss. It is important to be aware that being Deaf is not one thing - the Deaf community describes Deaf (with a capital D) people as those who were deaf from birth, and may come from families where there are generations of deaf members; they then describe deaf (with a lower case d) people as those who lose their hearing later in life. The third category is the hard of hearing. These categories demonstrate a range of deafness/hearing. To respect and support anyone with any hearing impediment some general points need to be remembered:

* Be sure to speak clearly (though not slowly, nor loudly) where the deaf or hard of hearing person can see your face. They may need to lip read.
* Establish eye contact before saying/signing anything to the member.
* If the member you are supporting uses sign language, be sure to check with his/her and/or the family what signs he/she understands.
* Never assume that the member is ignoring you, s/he may not have heard.
* Be sure to include the member in conversations by reminding others to establish eye contact before directly communicating with him/her, or by explaining afterwards what was being said.
* In workshops or group activities, be sure to convey information directly to the member, which s/he may have missed.

Following are some signs from the Makaton signing system - this is a sign language adapted from British Sign Language for those with learning disabilities.
EPILEPSY

What is epilepsy?

Most people think of epilepsy in rather stereotyped ways: what springs to your mind when you think about epilepsy? Do you expect to see a person convulsing and jerking on the floor? Perhaps some frothing of the mouth too? Some people also know about little “daydreaming” episodes too - sometimes known as petit mal. In fact it would be more useful, as some neurologists suggest, to speak of the epilepsies, rather than imply there is one epilepsy.

Epilepsy is a disorder, or condition, not a disease. Any person, given the right set of circumstances, could have a seizure during their lifetime. This would not necessarily be epilepsy - a single seizure may occur because of a particular set of circumstances, and never recur. Epilepsy is diagnosed, through a variety of tests and clinical observations, in people who have a tendency to have recurrent seizures. The seizures (commonly known as fits) may vary considerably from person to person, and also within the person. Some descriptions will help identify these below. Seizures occur because of excessive, abnormal electrical discharges in the brain. All our movements and everything we do, is controlled by the brain. Electrical impulses work in an organised fashion so that movements and consciousness can (usually) be relied upon to work in a predictable way. So that if the discharges become disorganised, it follows that movement and/or consciousness will be affected. For more detailed reading on this subject, see the suggested reading at the end of this section.

There are many myths about epilepsy which have stigmatised sufferers throughout the ages. Most commonly was the notion that sufferers were “possessed by demons” - although a ridiculous idea, it is still not uncommon for people to be afraid of someone having a seizure. Epilepsy can affect anyone, at any age, from any race or social class, and is not a mental illness. Although epilepsy does not usually cause brain damage, many people who have some brain damage will also have epilepsy. This is because the brain’s usual organised functioning will be affected by areas of damage, and so more susceptible to abnormal discharges.

Many famous and historical people had seizures: Alexander the Great, Julius Caesar, Dostoevsky. These days most people with epilepsy will have their seizures well controlled with drug therapy, but often still prefer not to let people know they have epilepsy for fear of ignorant responses. Even during this century, people were committed to institutions simply because they had seizures - they may have been perfectly well and capable outside of the seizures, but were locked away anyway. There is still much ignorance, and also misunderstanding, which makes life more difficult for sufferers than is necessary. At Kith & Kids we want our members who suffer from seizures, to feel accepted and understood, and to feel safe and have fun.
What might you feel when you are with someone who is having a seizure?

It is understandable, and very common, that people feel frightened and helpless when they witness a convulsive seizure. I have seen literally thousands of seizures over the years, and can still feel myself reeling at the most obvious types. We train everyone on our projects to be able to cope with convulsive seizures, and of course no-one is alone to cope, because we work 2:1. Also there are always others around to give additional support if it is needed. The most obvious seizures are actually quite rare, and we have sometimes had projects where not one of our members has had a seizure during the project. However, forewarned is forearmed! Treatments will be explained under the list of seizure types, but please remember, you are important too. When you have ensured that the person you are with is safe and comfortable, you may need time out for yourself, to get a cup of tea, have a hug, or talk. The person who had the seizure has probably had hundreds before, and will recover as they usually do - you have not! So be kind to yourself - and to the sufferer, who will benefit from having you feeling calm and supported, rather than frenzied and exhausted.

What types of seizure are there?

The list could be endless. Here I will outline the most common types of seizure. Before working with or be responsible for a person with epilepsy, there are ten simple, but important questions you need to ask, to be clear that you know that individual’s pattern:

1. What type or types of seizure does this person have?
2. What do these seizures look like?
3. How frequent are the seizures?
4. Is there a pattern to this person’s seizures? (ie, only while asleep? they come in clusters?)
5. How long do this person’s seizures last?
6. How long, and in what way, does this person usually recover?
7. Is there a “trigger”? (tiredness, stress, flashing lights)
8. Is there a warning? (loss of speech, colour drains, shouting, the person “feels funny” etc)
9. Is first aid usually required, if so what? (some people need drugs to be administered, eg rectal valium)
10. What drugs, in what quantities, and at what time must they be taken?

You will normally be given the history of the member you are assigned to, by staff at Kith & Kids. Then you will update this by talking to the individual if appropriate, or her/his parents. Parents will also tell you about any special precautions there are about activities like swimming, or if the student needs to wear a helmet.
Recognising seizures

There are many types of seizure, and each person manifests them in individual ways. The cause in the brain may be the same, but the behaviour observed may differ between and within individuals. Following are general guidelines on the most common forms of seizure, and what you need to do about them. You may be surprised to learn that many seizures are so subtle, that you may not notice them at all. It is still important to recognise they occur though, if you are to understand the member you are with.

Generalised Tonic-Clonic (sometimes still known as Grand Mal, the stereotyped convulsive fit)

Commonly the person will stiffen and fall; there may be some blueness around the mouth and/or some blood flecked saliva or frothing; convulsive movements (jerking) may be anything from rapid small shudders to quite violent jerking of all limbs. There may be incontinence on rare occasions.

Treatment

Try to protect the person from injury - move away any objects they might hit with their limbs. NEVER restrict movement nor try to put anything between the teeth, you could cause injury. Cushion the head. Time the seizure - this helps you focus on something practical, and you may need to consider giving drugs to those who require them. I always suggest “crooning” - that is, gently reassuring that things are fine, it will stop soon etc. This serves two purposes: 1. It reminds you that calmness will help, and keeps you and anyone else around calm. 2. If the person can hear as they begin coming out of the seizure, they will hear a soothing rather than panic stricken voice. As soon as the jerking has stopped, put the person on her/his side (in recovery position which you will be taught), to aid breathing and prevent the tongue rolling back. Stay with the person, reassuring them until s/he has recovered.

Complex Partial (affecting a specific area of the brain, but not all of it)

These may start with an “aura” (for some this may be a particular smell or sound) or warning. The person may appear confused or distracted, may be unable to speak. They may repeat a series of movements, like plucking at the clothes or lip smacking, or unusually, running away.

Treatment

Do not try to restrict movement. You may need to prevent danger by blocking exits or standing in front of the person. Talk quietly and reassure - sometimes the sufferer can hear during one of these seizures, even if they can’t speak or respond to what you are saying, they may feel frightened if your tone is harsh. Try to time the seizure. Stay with the person till s/he is fully recovered.

Generalised Absence (sometimes still known as petit mal).

Although the person does not fall, s/he is completely unconscious for the duration of this
type of seizure. S/he may simply stare - may look as if s/he is daydreaming, may blink or have slight twitches. These usually last for only a few seconds, and then normal activity begins again. These may occur in clusters, which may leave the person confused.

**Treatment**

The person is often unaware that this type of seizure has occurred, but may feel confused if they missed something happening (ie someone coming into the room), or missed some information. Be sensitive - go over or explain anything that was missed. Note what happened, and observe to be sure this was an isolated seizure. Be careful around roads if this is a frequent type of seizure for this person. It is very easy to miss these, and because they are unconscious they may be unaware of danger. The body is still going, but consciousness is switched off.

Other common types of seizure are very brief, and involve the person dropping to the floor - muscle tone gone for that second, and then the seizure is over. Treatment is only required if injury has occurred. Myoclonic jerking - these may be isolated jerks of the whole body or limbs, or periods of regular jerking movements. The treatment again is reassurance, sensitivity, and timing prolonged periods of jerking.

**N.B.** It is not usually necessary to call for an ambulance when managing epileptic seizures, especially when you know that person’s history and pattern of recovery. It should be considered straight away in the following circumstances:

1. This is the first seizure for this individual who has no previous history of seizures.
2. Injuries have occurred during the seizure, e.g. a cut that needs stitching.
3. The convulsive part of the seizure shows no sign of stopping after 10 minutes, or 2 minutes longer than is usual for that person.
4. If a second seizure occurs without the person regaining consciousness since the previous one.

At Kith & Kids activities and projects there will always be workers and others who are familiar with all Kith & Kids members. So you will never have to face situations alone, or without prior knowledge of the member’s seizure history. It is reassuring, though sometimes surprising, that a person can have what looks like a terrible seizure during the morning, and be active and happy in the afternoon. Most of the members in Kith & Kids who have long established epilepsy are used to their seizures, and get on with their lives in between happily. With sensitivity from those around them, their lives are greatly enhanced.
AFFECTION, TOUCH AND SEXUALITY

On our projects and activities you will be meeting lots of new people. Some will be volunteers, like yourselves, some will be young people with learning and/or physical disabilities, some will be parents of these young people, how do you greet them for the first time? Would you behave differently towards any of the people in the groups mentioned above?

How would you feel if a complete stranger threw their arms around you on your first meeting?

We’d like you to think about these questions, because we want you to feel comfortable with your actions on this project.

Some of our young people are extremely and openly physically affectionate. Some find any kind of physical contact difficult to cope with. All of us (whether physically or learning disabled or not) will fall somewhere along this continuum. How we feel about expressing ourselves physically may also vary from one relationship to another, and in different situations.

In the past we have found that some of our volunteers have wanted some guidance as to what is, or is not, appropriate behaviour.

**** The major point we’d like to convey here is that we want you to feel comfortable. This may mean saying clearly: “I’d rather not hug you, but I’d like to shake your hand”. Or it may mean keeping a slight physical distance if you feel you are being drawn into an unwanted (at this time) embrace. Neither of these approaches need to be rejecting, if put over clearly and sensitively.

**** If you EVER feel uncomfortable about something you have felt or done, or about something someone else has done - there are always people around (Co-ordinator, Volunteer Co-ordinator, Parents, Professionals, other Volunteers) who want to listen - who are ready to hear, without judging.
Touch is a positive element in all our lives, but we need to be very clear about the message we give with our touching - whether this is just a pat on the back, a touch on the arm, a hug, a kiss - whatever. If this is true for all of us, it is also true for people with learning/physical disabilities. Our relationships change over time, and our physical expressions in them change too. It may be more difficult for young people with disabilities to understand this, if other people do not treat them equally in this most important area. By asserting your rights and feelings, you are helping others to assert theirs.

Some young people with disabilities find it more difficult than others to express their developing sexuality in “socially acceptable” ways. There may be times when you find yourself with someone who is masturbating, or behaving in overtly sexual ways. If this is a feature, at this time, with any of our young people who you are supporting, you will be told, by the parents concerned, how they usually manage the situation. If you are not sure, or find yourself feeling uncomfortable or embarrassed, TALK!! to one of us - we have seen and heard it all before!

Young people with disabilities are no different to young people without, in developing sexually. However, they may have less inhibitions, and may need help in expressing their sexual needs in ways in which will not lead them into danger (or exploitation or prosecution), and which are socially appropriate.

Again, if you need more clarification on any of the above thoughts, please do come and talk to co-ordinators, parents and/or workshoppers.

REMEMBER:  BE COMFORTABLE in your actions
         ASSERT YOURSELF
         BE CLEAR about what you want
         TALK, TALK, TALK, TALK .......

![Would you like to talk about it?](image)