

No9 - JANUARY 1996

Asperger United is a self-help group run by and for people with Asperger Syndrome. Its aim is to put people with the condition in touch with one another and to provide them with information so that they can lead more independent lives.

The Asperger United Newsletter is produced by an editorial group consisting of the two current Editors; David Wright & Ian Reynolds; Pam Yates from The Maudsley Hospital's Home Based Team For Autistic Individuals with additional support from The National Autistic Society.

WITH THANKS

Dear Readers

As we near the end of our second successful year, we also sadly near the end of David Wrights year as Editor. David has done a fantastic job, campaigning and working endlessly on behalf of The Newsletter and its readership. A big thank-you to you David and best wishes in your future chosen career.

A big thank you to Ian Reynolds to for his support and as sub-Editor. Ian will taking over as editor next year and we hope to have a new sub-Editor in place by then as well so watch this space to find out who it will be!!

Mark and I would like to take this opportunity to wish you all a very happy Christmas and successful New Year. Keep the letters rolling in and your ideas on what you would like to see in your newsletter.

Last but not least, thank you all for all your letters and articles. Unfortunately it is not always possible to publish all of them but we will endeavour to publish as many as possible.

Parting Shot!

Dave Wright has sent a letter giving details of general self help organisations, some of these addresses will be given in the next issue of Asperger United.

Highlights - Article from Thomas Madar

Asperger Network (letters from readers)

- 1) Nigel Wood of Queens Park Farm
- 2) Miss K Nichols
- 3) Richard Exley

"Under the Spotlight" -

This is a new section to be devoted to poems, drawings or short stories written by someone with autism.

- 1) Poem by David Miedzianik "The day I became someone else"
- 2) Drawings by Tim Loder

HIGHLIGHTS

A PERSONAL VIEW OF AUTISM

by Thomas Madar

On the following pages Thomas Madar offers a personal view of the characteristics of autism and their possible causes, advantages and disadvantages.

The Primary Characteristics of Asperger Syndrome

Introduction

Listed below are what I believe to be 10 primary characteristics of people with Asperger Syndrome. Though they certainly feature in my life, the acceptance of these characteristics as fact is subject to verification.

A. A difficulty in picking up the unwritten rules of society

This difficulty is caused by an impairment in the way the brain receives and processes incoming implicit information which people use to conform to the unwritten rules of society. The affected people will fail to automatically acquire the many implicit rules of living, making it necessary for him to be explicitly instructed. Thus these rules are learned in the same way as an academic subject. This characteristics is modelled in Fig 1.

Advantages

The person may display a surprising degree of originality in many ways by not being so bound by the rules of society.

Disadvantages

The person will have difficulty in internalizing unwritten rules and facts governing the following areas and more:

- a) Dress, appearance and personal hygiene
- b) Living independently (cleaning, laundry, shopping, cooking, management of personal finances).
- c) Tastes of fashion (music, dress etc).
- d) Interpersonal interaction (social behaviour, interpersonal conversation).
- e) Finding a job.

This will make the skills of living independently and making friends hard to acquire.

The person will be naive to the point of social embarrassment when presented with a joke or a figure of speech which demands knowledge of an obvious fact which he/she has not yet acquired.

B. A difficulty in picking up non verbal signals from others

This difficulty is caused by an impairment in the brain's ability to sense non verbal signals (eg emotional states) from other people. This difficulty is modelled in Fig 1.

Advantages

None.

Disadvantages

The person will miss signals which cause others to adjust their verbal communication to the recipient's age, status or their emotional state, and so will appear to lack empathy.

Without the ability to pick up tell tale danger signals, the person will be fair game to unscrupulous people.

The person is impaired in interpreting figures of speech and some jokes because he/she has difficulty perceiving the in-context signals of the speaker. This makes him/her appear naive and can cause social embarrassment.

C. A difficulty in perceiving what other people are thinking of or will think in given situations.

This difficulty is caused by a peculiarity of personal make-up. When engaging in an activity which affects other people (for example, writing a letter), the person is unlikely to have their future thoughts of his/her mind. Thus he/she is not restrained from executing that activity in an offensive or peculiar way ... with rejecting consequences.

Advantages

The person is likely to be brutally honest when the situation deserves it. For example, an obnoxious parent-in-law makes a real nuisance of him/herself when staying at a child's home, departs, then rings up and asks if he/she will be missed, then that parent will get a well deserved 'no' rather than a white lie 'yes'.

Disadvantages

The person is more likely to commit a peculiar or offensive act or habit because he/she will not realise its impact on others. This will result in a degree of disapproval, rejection and isolation from other people and will adversely affect social and career prospects.

The person has difficulty in detecting dishonesty and so very vulnerable to being 'taken for a ride' by unscrupulous people.

D. A difficulty in formulating and verbalizing communicable thoughts.

This difficulty is caused by an impairment in the way the brain formulates thoughts and converts them into a linear sequence of words in response to a stimulus such as criticism, then presenting these at the right speed, with the right tone of voice, and accompanied by appropriate non verbal signals for the maximum impact. This characteristic is modelled in Fig 2.

Advantages

A difficulty in conversation formulation and delivery means that the affected person is quiet. In many situations, particularly in the office, this is a welcome attribute.

Disadvantages

Any form of communication impediment is likely to radiate an impression of low intelligence, lack of confidence, dishonesty etc and so will render the person liable to be discriminated against and be subject to a degree of social isolation.

The person has great difficulty in occupations requiring advanced communication, leadership and/or persuasion skills, for example, school teacher, manager, salesman.

The person has difficulty in defending him/herself against criticism and winning verbal arguments and so is likely to lose face and be trodden on.

The person has difficulty in formulating effective answers to job interview questions unless thoroughly prepared for and rehearsed in advance.

The person has difficulty in communicating a need or an emotion effectively, resulting in the frustration of this not being met.

The person is likely to have difficulty in arranging words and sentences for written work such as course essays, resulting in a long completion time.

E. A raised anxiety state

This characteristic is caused by a feature of the person's make-up and may be aggravated by the problems by characteristics A-D in the person's life.

Advantages

A fear of the consequences of being disorganised will make the person very organised in everything he/she arranges. In most situations, this is a very welcome trait.

A fear of the consequences of being incautious will make the person exercise extreme caution in what he/she does.

A fear of the consequences of dishonesty will make the person honest and of high integrity, very welcome in our times.

Disadvantages

A fear of the consequences of retaliation will make the person hesitate to defend himself or be nasty when the situation calls for it. This makes him/her vulnerable to be trodden over by stronger people and is a disadvantage in any occupation requiring good leadership and/or persuasion skills.

An impression of chronic anxiety implies social inferiority to some people.

The person becomes unreasonably worried when something does not go according to plan, for example, a normally punctual bus being late.

Other fears may bring other restrictions in the life of the person, for example, a fear of crowded places restricting access to shopping centres on Saturdays.

F. Sensitivity to small discrepancies

This characteristic is caused by a feature of the person's make-up, but may be aggravated by anxiety, and results in the person being acutely sensitive to anything which is even slightly out of order.

Advantages

The person is very scrupulous in anything which he/she does, paying great attention to detail to produce a high quality piece of work.

Disadvantage

Scrupulous attention to detail takes time and is disadvantageous in situations where time is money and/or crucial tight deadlines have to be met.

Small annoyances, for example, a shop sold out of a favourite brand of soap, may cause the person severe irritability and, occasionally, loss temper.

G. Concentration difficulty

This difficulty is caused by an impairment in the ability of the brain to subdue other thoughts in order to focus attention on a particular task for a sustained period of time. The person daydreams and has difficulty in restraining his/her mind from wandering onto other things when trying to do a piece of written work or listening to a lecture.

Advantages

None.

Disadvantages

Poor concentration lengthens the time taken and is disadvantageous in situations where time is money and/or crucial tight deadlines have to be met.

Poor concentration plays havoc with the input of information from lectures.

H. Clumsiness at sports

This difficulty is caused by a impairment in the brain's ability to finely co-ordinate a person's body movements when swimming, jumping, throwing an object or catching one. The person has difficulty in mastering sports and games requiring more than the simplest co-ordinated body movements.

Advantages

The person is more likely to be excused games (an often hated activity) at school.

Disadvantages

Likely lead to social isolation and low status in cultures where prowess in sport is valued.

I. A very focused set of interest

This characteristic is caused by a feature in the person's make up. The person has a keen interest in a very highly specialised area, for example, the advertising and packaging of sweets.

Advantages

The specialism may be the basis of a worthwhile hobby, better than watching television.

The specialism may lead to some good career openings.

Disadvantages

The person may be regarded as peculiar by general society.

Concentration on the specialism lead to a lack of breadth of general knowledge.

J. Islands of extraordinary ability

This characteristic is caused by an extraordinary efficiency in one or more areas of the brain not affected by characteristics A,B,C,D,G and H, and results in sometimes a very superior ability in a particular area. These may range from an above average ability to recall the prices of goods in shops to extraordinary gifts in music and painting.

Advantages

The gift(s) will compensate for the person's disabilities, and enable him/her to contribute effectively to society. An effective path to fulfilling employment.

Disadvantages

None

Conclusion

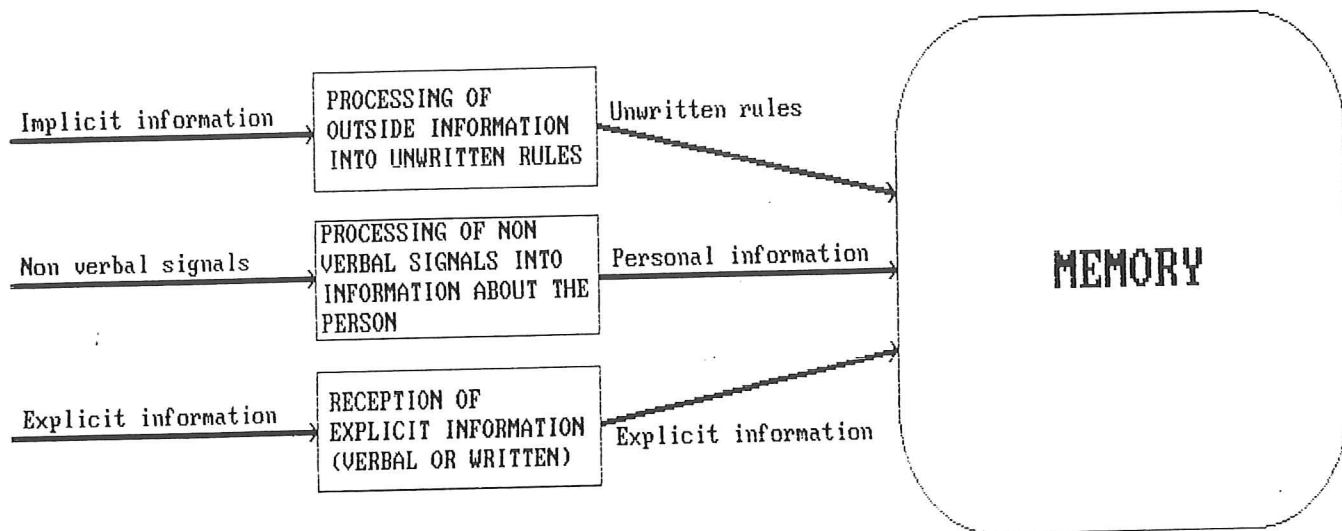
From the above, Asperger Syndrome appears not as one disability, but as a family of characteristics of which most have a disabling affect in our society. In most environments, characteristics A to G will frustrate a person's social and career aspirations, frequently reducing him/her to an undeserved position of insignificance. Continued frustration will exacerbate anxiety and induce a state of chronic depression as modelled in Fog 3. (This may be confirmable by characteristic levels of serotonin in the brain and the blood).

Given understanding and patient parents, an education in a school where teasing and bullying is eliminated and an occupation appropriate to interests and abilities, there is little reason for a person with Asperger Syndrome not to live a happy and fulfilled life.

FIG 1.

Diagrams to compare the reception of outside information between a non disabled and an asperger's disabled person.

A NON DISABLED PERSON



AN ASPERGER'S DISABLED PERSON

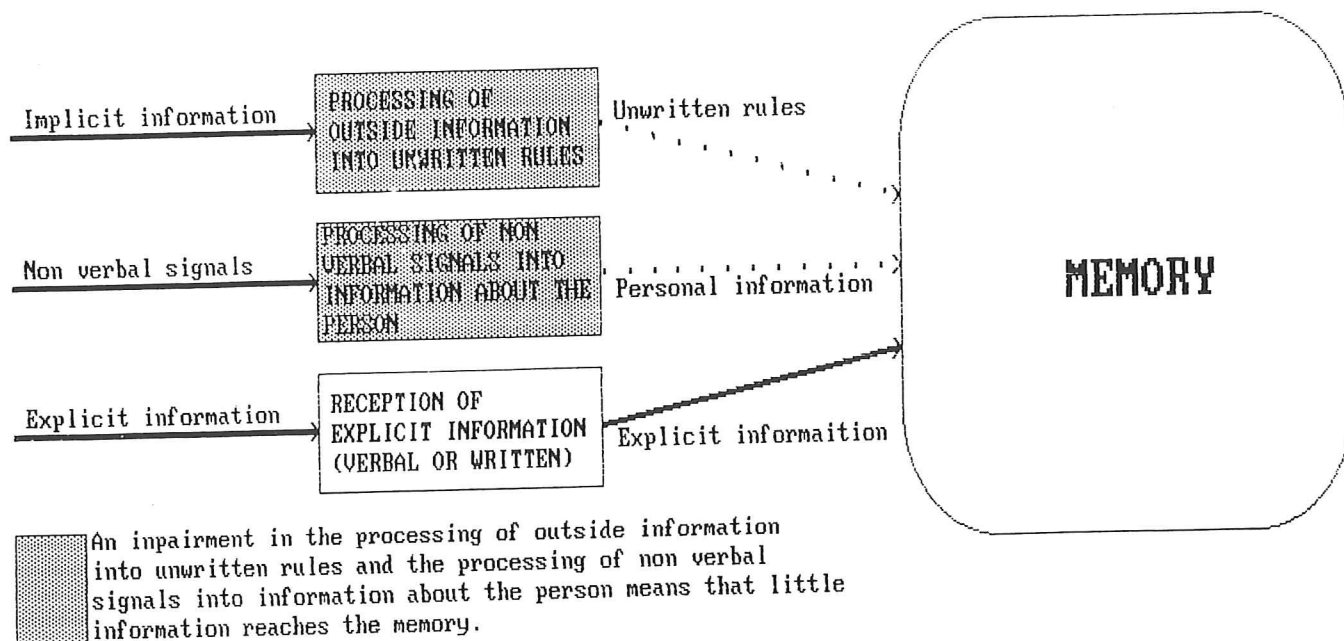
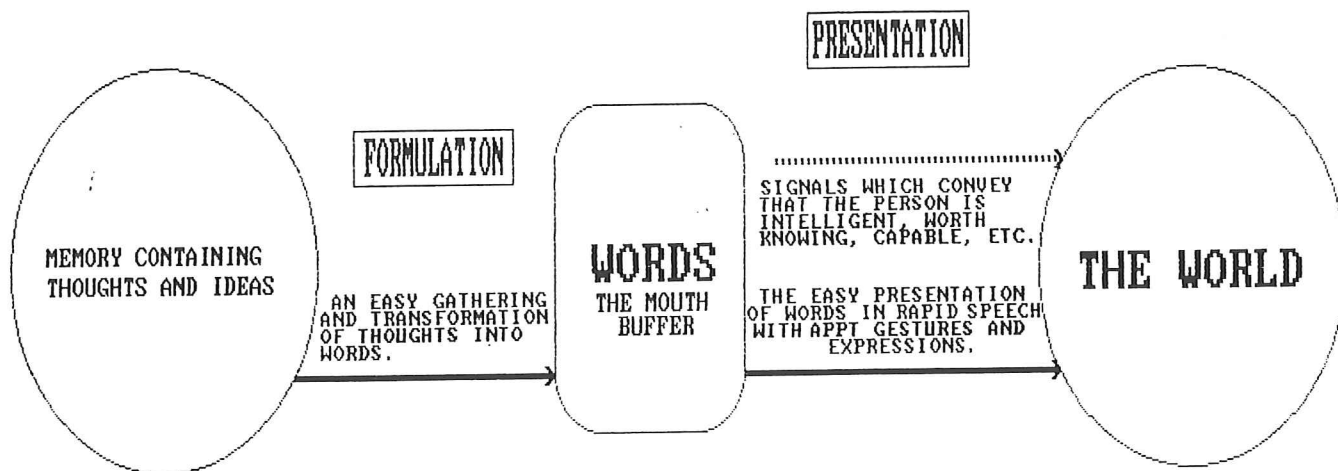


FIG 2.

Diagrams to compare the processing of thoughts and ideas into verbal communication between a non disabled and an asperger's disabled person.

A NON DISABLED PERSON



AN ASPERGER'S DISABLED PERSON

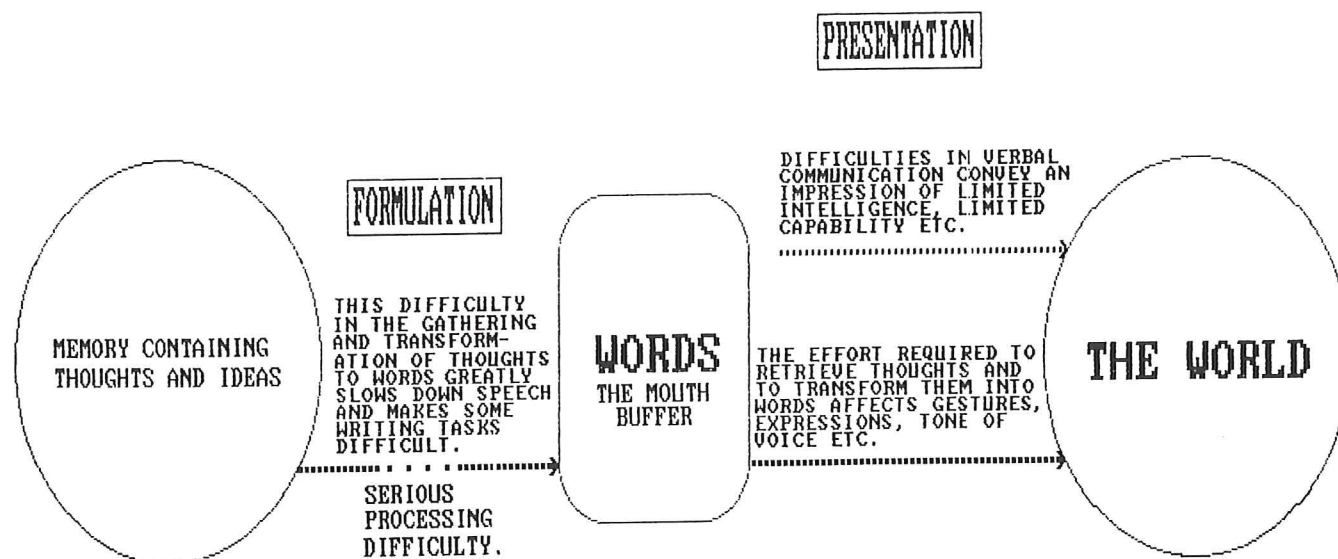
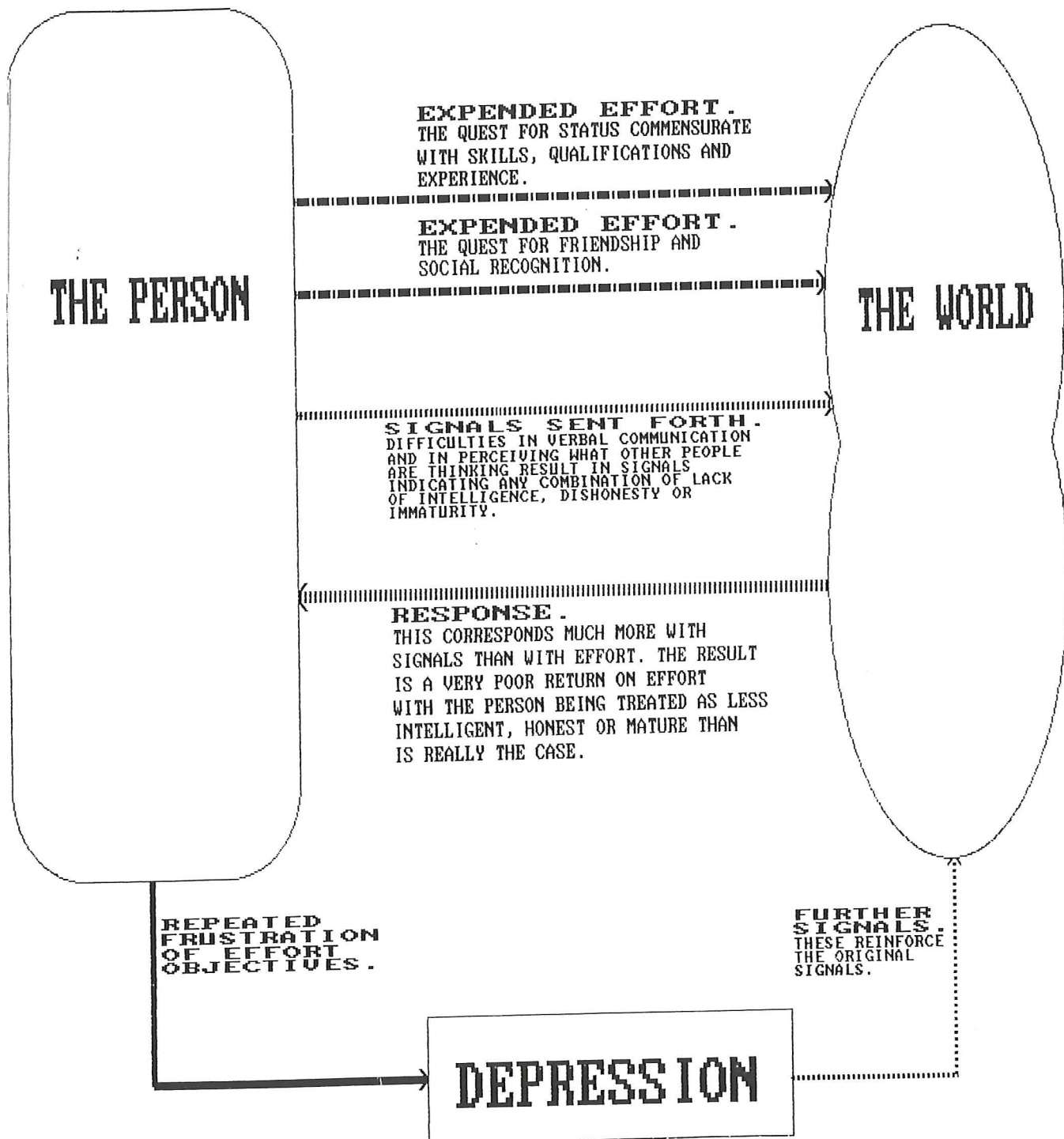


FIG 3.

Diagram to show causes of frustration and depression in an able person suffering from autism or Asperger syndrome.



Asperger Network

WANTED - A Girl in her 20's from Birmingham to be a Penpal!

I am 23 years of age and I like transport, The Royal Mail and music such as XTC, Elastica, Blur, 70's and 80's music, Old grey Whistle Test, DJ Heaven, Sounds of the 80's etc.

From Nigel Wood
Queens Park Farm

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Hello everyone,

My name is Kathleen. I'm 29 years old and I was diagnosed as having Asperger Syndrome last year. I would like to hear from others with Asperger Syndrome.

My interests are:- art, penpals, watching movies/TV soaps/videos, 1950's and 1960's music, animals, reading, doing jigsaw puzzles. My favourite stars are Arnold Schwarzenegger and Elvis Presley. It doesn't matter to me what your interests are though!

From Kathleen Nichols
London

* * * * *

My name is Richard Exley, yes I used to edit Asperger Syndrome, I am twenty-one years old. I currently live in Liverpool but originally come from West Yorkshire. At the moment I am involved with many groups, local societies and project to help children, adults and their families who have autism/Asperger Syndrome, autistic features or autistic tendencies. As you can appreciate, this takes up a lot of my time, but I do have some spare time where I play and watch badminton, cricket, football - I also go swimming. I have a girlfriend who I have been going out with for over two and a half years, she is very special to me. Hopefully one day I would like to get married and have a family of my own. So if you'd like a penpal or a friendly chat, please do get in touch - all letters and phone calls shall be answered.

From Richard Exley
Liverpool

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Under The Spotlight

POEM by David Miedzianik

'The Day I Became Someone Else'

Well the clock went past 12 midnight
This was when I became someone else
Well I thought it was great to be someone else
It made a change not to be on the sick for once
Well 9AM I set off for town
This was a day when people wanted me around.

Well it made a change to be someone else
Things were seeming better, while I was under this spell

Well I got talking to some lasses
They said they'd meet me maybe someday
They'd no doubt meet me after, this spell had gone away
It was great to have a clear mind
Before I was on so many pills it was unkind
I hoped to find a lass before the day was up
If I couldn't get one this day then it'd be tough
Mind you I'd had a life-time of things being rough.

Well it made a change to be someone else
Things were seeming better, while I was under this spell.

Well I thought I'd make the most of fall this
So I stopped down town to get to know people
Some people thought I was a stranger from out of the blue
Others knew who I was, someone new
Mind you on this day my bus-pass wouldn't pass
Paying full fare made me feel like dirt.

Well it made a change to be someone else
Things were seeming better, while I was under this spell.

Well a lot of people seemed to like the new me
It was great although the day was going by, by now
I looked at my old library ticket under David's name
I wondered after this would things ever be the same
I had an identity before even though it didn't please me
Now people see someone else in me
Has this really happened or is my mind at sea
Who cares as long as I've still got the house keys

Well it made a change to be someone else
Things were seeming better, while I was under this spell.

Well the day was getting over
It was now 11.30PM at night
this was a time when all there was, was moonlight
That doped-up feeling was starting to come back
I was starting to think again of all life lacks
I also knew tha this day would never come back.

Well it made a change to be someone else
Things were seeming better, while I was under this spell.

* * * * *

HAPPY NEW YEAR

GREETINGS FROM

Mark, David, Ian and Pamela



ALPS FROM PLANE
TIM LODER

XXIX



ALLY
WAPES
CAPITAL

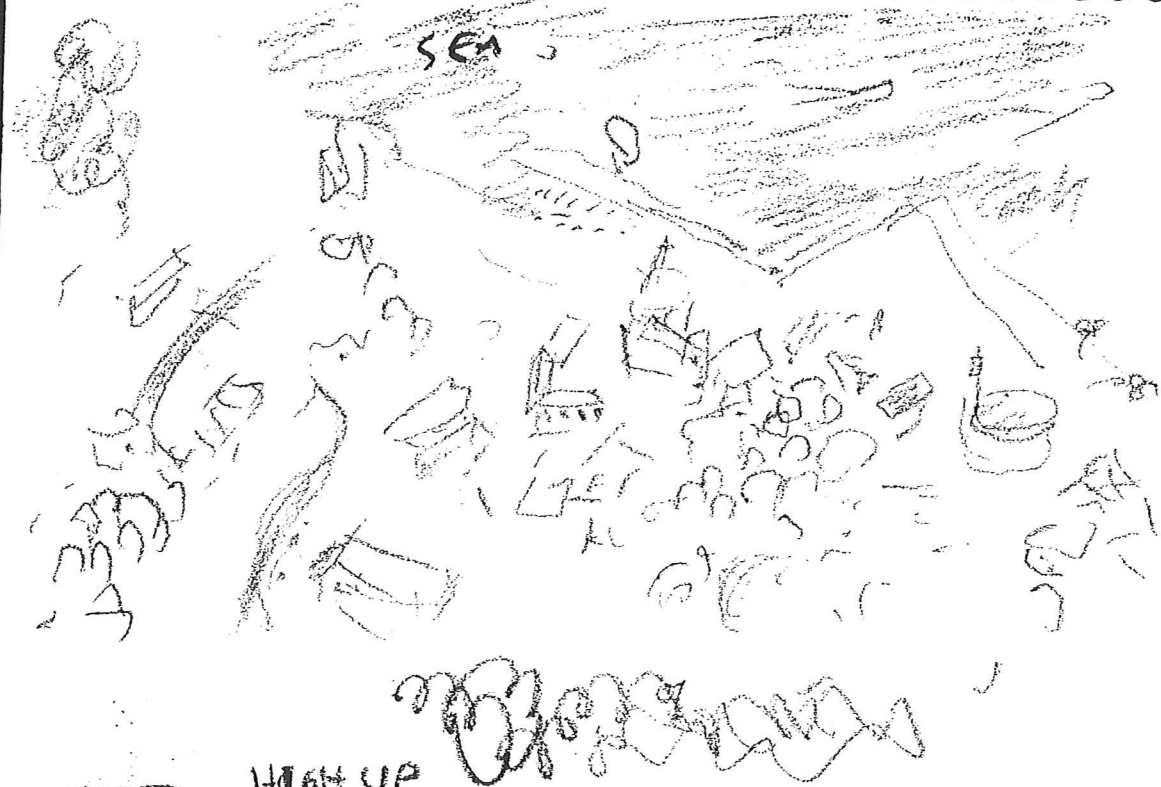
TIM LODER 7.26/9/95

IX



XV

HILL OFF
AMALFI.
TIM LODGE



XVI

HIGH UP
VIEW OF POSITANO FROM SANTA MARIA
TIM LODGE CASTELLO