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**First, persons: Discovering Internet accounts of men
with autism spectrum conditions**

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ABSTRACT

Autism spectrum condition (ASC) is a developmental condition in which individuals have difficulties in social interaction, communicative development and imagination, and exhibit a restricted range of interests. Although rates of diagnosis are rising, few studies have taken a first person perspective, and explored how adults with ASC describe their own experiences. The paper presents clinical qualitative research into ASC, using autobiographical accounts and Web pages created by men with ASC. A number of life stories posted on the Internet were collected and analysed. Results brought into question the received wisdom that ASC is a disability, with many participants suggesting that difference is a more useful framework for understanding ASC. The study proposes several themes that may assist helping professionals to work therapeutically with young men with ASC.

ACKNOWLEDGEMENTS

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[A]nd now I come to the root of the matter, the reason for my starting a diary: it is that I have no real friend. (Anne Frank, 1954, p. 14.)

INTRODUCTION

Children and adults are diagnosed with autism spectrum conditions (ASC) if they exhibit problems with social interaction, communicative development and imagination, as well as marked repetitive behaviour or a restricted range of unusual or narrow interests. Diagnostic convention holds that individuals with autism with normal IQ are labelled as having "high-functioning autism" (HFA). If an individual meets the criteria for HFA yet does not have a history of language delay or abnormality in communication, they are classified as having Asperger syndrome or AS (American Psychiatric Association, 1994). The focus of this study is on people with HFA or AS, as people with an IQ below normal have a disability, due to the presence of retardation. Because there is no clearly defined distinction between the diagnostic categories of HFA and AS, this paper employs the protocol of autism spectrum conditions (ASC) in describing the participants. The diagnostic criteria for ASC is an evolving and controversial issue, particularly for those high-functioning individuals who are not intellectually disabled (e.g., Mayes *et al.*, 2001). This leaves room for some confusion regarding diagnostic terms and it is likely that similar individuals can be diagnosed with Asperger Syndrome, High Functioning Autism, or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), depending upon where, and by whom, they are assessed.

Traditionally, psychologists have diagnosed autism in negative terms, either as a developmental disorder, a psychiatric condition, or a disability. Since the condition was first identified in the 1940s, people with autism have been regarded as deficient, impaired, or ill. This is attributable to their great difficulty in "reading" social signals like facial expressions and dealing with the reciprocal flow of conversations. Because people with ASC look "normal", those without autism can misinterpret their difficulties in social interaction and "oddness" as being aloof or rude, provoking ridicule and intolerance, and resulting in discrimination. This paper presents clinical qualitative research into the narratives of adults with ASC, based on autobiographical accounts and Web pages posted on the Internet.

The expansion of the Internet has given access to a number of traditionally marginalised groups in society, and individuals and families affected by ASC have a significant presence on the World Wide Web. In the interests of pursuing life stories in an "everyday" context, the study has employed an unobtrusive methods design to discover and analyse Internet-published autobiographical accounts and web pages of young men with autism spectrum conditions.

THE RESEARCH SETTING

Background

The following two research questions have driven this study:

1. What are people with ASC saying about themselves when they post their life stories on the Internet?

2. What elements in the autobiographies can be used by families, educators, psychologists, and other clinicians to assist other individuals with ASC?

Until ten years ago, the prevailing scientific opinion was that autism spectrum conditions were a rare condition. However, recent diagnostic inclusion of "milder" cases along the continuum of core characteristics (the so-called "triad of abnormalities" first outlined by Lorna Wing in 1981) has turned this opinion around. For example, the autism spectrum conditions are more prevalent in children than cancer, Down Syndrome, or spina bifida (Filipek et al, 1999). As the literature into autistic spectrum grows, researchers and clinicians have noted the rather unspectacular finding that children with ASC grow up to become adults with ASC. In his original paper, Asperger (1991/1944) wrote that the prognosis for individuals was generally positive, due to their normal range cognitive ability and the social value of their special skills and interests. He also pointed out that individuals of very high ability could find employment in areas such as mathematics or science, citing the relatively successful lives of their parents as examples. In the last twenty years, rates of institutionalisation for children with autism have fallen dramatically, and

participation in work or training has climbed equally dramatically (Howlin, 1997). While levels of care and support for children may have improved, adults living with ASC are still among the most vulnerable and socially excluded groups in society, discriminated against in employment, education, and access to social services (Barnard *et al.*, 2001). Further, it seems very likely that many adults with ASC experience high rates of chronic anxiety and depression, and may be at greater risk for completing suicide (Wing, 2000).

Both Kanner (1943) and Asperger (1991/1944) noted the excess of autistic boys over girls, and Asperger syndrome appears to be more common in boys than in girls, although the reasons for this remain unclear. Hans Asperger (1991/1944) described the condition as an "exaggerated" pattern of male personality, and one prominent author has argued that autism may be an "extreme form" of the male brain (Baron-Cohen & Hammer, 1997). Fombonne (1998) found that there are almost four males for every female, taking into consideration all ranges of intellectual ability. The male/female ratio skews heavily towards males as cognitive ability increases. At the lowest ability levels, the ratio of boys to girls was only 2:1, yet at the highest ability levels, the ratio may be 15:1 (Wing & Gould, 1979). Tantum (2000) concurred that, for those individuals in the very high to superior ranges of intellectual abilities, males are strongly overrepresented. In a society that is placing a higher value on "emotional intelligence" (Goleman, 1995) and social adroitness (traditionally seen as female attributes), males with AS or autism find themselves on the outside. Developmental disorders such as reading delay, hyperactivity, clumsiness, stuttering, and Tourette's syndrome affect three to four times more boys than girls and conduct and oppositional disorders are at least twice as common in boys (Kraemer, 2000). Across the

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developed countries, the suicide completion rate in young men is several times higher than that in young women and has doubled in New South Wales over the last thirty years (Centre for Mental Health, 2000). Compared to girls, boys are generally more difficult to care for, they tend to be more excitable, and their attachment is more affected by parental unavailability, insensitivity, or depression (Kraemer, 2000)

The research gap

Although there are some studies drawing on spoken accounts of people with ASC or autism (e.g. Ghaziuddin *et al.*, 2000; Hurlburt, Happe, & Frith, 1994), there are even fewer discussions of written narratives by people with ASC, with a few exceptions (e.g., Happe, 1991). In one example, Volkmar and Cohen (1985) analysed a narrative written by Tony W., a young man with a history of autism. According to the authors, Tony's narrative had interpretable grammar, but was "deficient in grammar organisation, word choice, spelling, and punctuation, [making] the statement difficult to follow" (p. 255). Loveland and Tunali (1993) proposed that people with ASC have a "core" deficiency in their ability to construct narratives, and that they do not have the required narrational means to express past or present experiences, in order to give a coherent meaning to their accounts. Bruner and Feldman (1993) wrote that "people with autism display a failure to be able to organise the narrative structures through which culture organises its expectations about how people feel, think, and believe" (p. 288). They added that research findings supported a conclusion that people with autism convert the "personal world of intention-regulated social experience into an impersonal world of causally-driven events" (ibid). This conversion means that people with autism come up with "adequate" but bizarre interpretations of the interpersonal world, leading to a strangeness in their speech and mannerisms, giving

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those without autism a "disturbing sense that they are interacting with someone who is, as it were, outside the culture" (ibid).

The majority of information and empirical research has been written from the perspectives of other informants, either clinicians, educators, or parents. While these "third-person" approaches have proved invaluable in furthering knowledge of autistic spectrum disorders, the experience of the person with ASC has been relatively neglected in the literature. Yet, in seeking to explain and measure, using an objectivist epistemology, psychologists and other researchers seem to be missing out on the "lived lives" of people with ASC.

QUESTIONS OF METHOD

Participants and data collection

The research collected non-elicited autobiographical accounts of people with ASC available over the Internet. The participants were men living with ASC who have posted autobiographical accounts on the Internet. This research project initially received ethical approval in November 2000, but I soon struck two major problems. First, my initial approaches to an ASC social group had elicited a number of verbal agreements from young men to take part in the project. However, when I next met with the group, having gained ethical approval, only one participant agreed to take part in the research. It appeared that the young men were hesitant to engage in such an intimate social encounter. However, during preparatory research for the project, I discovered a great number of websites about autism spectrum conditions written by parents as well as people with ASC. Therefore, the focus of the study changed from gathering interview material to using the Internet as the primary source of data. This approach had the benefit of allowing access to a larger participant population, with the view of enriching the diversity of accounts. The emergence of information technology is not only changing the way people interact with computers, but the way people interact with people. The Internet may be approaching the status as "a general communication interface … creating a new psychosocial space … for social relationships, roles, and a new sense of self" (Riva & Galimberti, 2001, p. 1). Computer mediated communication (CMC) is a powerful tool for investigating the subjective experiences of young men with autism spectrum conditions. People with ASC are seemingly "primed" to feel comfortable with computers. Their ability to tunnel their attention suits a computer environment, which has very clear cut

boundary conditions, and is rule-governed and predictable. Computers also offer a sense of personal achievement as well as providing an opportunity for valued contribution, in the eyes of parents, educators, and society as a whole. The usual baggage of judgement and nonverbal communication processes is less influential on the participants' reports. Further, my clinical experience has shown that young people with ASC are more likely to disclose their emotional selves in cyberspace. With the proliferation of web sites and autobiographical accounts in the public domain, researchers have an opportunity to develop theoretical frameworks and analytical repertoires based on the self-descriptions of young adults with ASC.

The unobtrusive nature of the research had both positive and negative implications for the study. On the plus side, it meant that the data was "naturalistic", that is, it conveyed the writings in an everyday setting, contributing to less "manufactured" or "contrived" information. Because the researcher was not eliciting opinions, it is likely that the accounts more fully account for the experience of men with ASC. However, non-elicited data meant that the participants might not be restricted to those young men with an independently confirmed diagnosis of Asperger syndrome or ASC. In an attempt to address this difficulty, any accounts that did not specifically describe an incident of a "formal" diagnosis (either by a pediatrician, psychiatrist, or psychologist), were excluded from the study. I started with the web sites of the national autism associations in the developed countries. I then looked for information on the site that could lead me to personal web pages of people with ASC. The text has been used as it appears on the Internet, with no alterations. Because of its very nature, it is impossible to determine whether the example I have used is "true" to the original. In all, 16 accounts were collected on the Internet, and 2 from

autobiographical accounts published in Schopler *et al.* (1998), as supplementary

material (see Appendix I for the references and Internet addresses).

Analytical framework

The study has used four main interpretative frames through which to analyse the texts.
A grounded theory attempts to generate theory from the case study material (as well
as from other texts of interest), and places emphasis on participants' own accounts of
events and meanings (Glaser & Strauss, 1967). The second frame is based on a
phenomenological method, which can illuminate the presence of meaning in the
experience of participants in psychological research (Polkinghorne, 1989).
Understanding people living with ASC casts light on a group of people who appear to
experience the world in qualitatively different ways from that of most people, and
serves as a fine example of the confusion that exists when attempting to define
notions of "normality" and "eccentricity".

The third interpretative frame of analysis comes from the "narrativist" turn in the
social sciences. Temple Grandin (1995) and Donna Williams (1994) have been
successful in furthering understandings of autism through popular autobiographical
accounts, yet these narratives have encouraged few researchers to investigate autism
from a narrative, or life story perspective. Personal stories are not just a way of
telling someone about a life, they are the means by which one's identity is fashioned.
The story exposes the meaning and subjective interpretation given by the person to his
or her life and to the various events that occurred during their life span. Jerome
Bruner (1986) maintained that people both organise and constitute their experience of

the world through narratives: stories, myths, excuses, and plots that have a beginning, middle, and end. Narrative importance lies in its being one of the main forms through which people perceive, experience, and judge their actions and the course and value of their lives (Hyden, 1997). Stories by people with autism are important because they give professionals a glimpse into subjective experience, and because they offer a "royal road" to understanding the consciousness of autism. Narrative self-representations can aid understandings of how people with "mental disorders" attempt to deal with their lives as well as clarify the problems of identity that, for example, a pervasive developmental disorder brings with it. Oliver Sacks (1985) has emphasized the importance of the "illness narrative" in helping health professionals to gain a more detailed clinical picture of the patient. The narrative of ASC creates the narrative of self and identity. The condition is expressed through a narrative, and the narrative is crucial in the presence of the condition as well as the way in which the condition affects the life of the narrator. Because to all intents and purposes, the condition *is* the narrative, the "personal narrative does not merely reflect illness experience, but rather contributes to the experience of symptoms and suffering" (Kleinman, 1988, p. 49).

The fourth frame is one based on a discourse approach (Potter & Wetherell, 1987). Discursive psychology is a "catch-all" term to describe a number of theoretical and methodological approaches that privilege the study of language and text in constituting meaning (Willig, 1999). Participants' language is productive of a version or versions of "reality", rather than representing "reality". Therefore, people's accounts are constructed (intentionally or otherwise) and perform certain functions. The seeming inconsistency and variability in language reveals that speakers can draw on different linguistic repertoires in their attempts at "meaning-making." This

research will also examine the participants' accounts in relation to the power relationships of social structures such as psychiatry and clinical psychology that are responsible for the occasioning of these discourses. Discourses of ASC construct a number of subject positions for both participants and professionals. As a diagnostic entity, ASC has enormous potential to construct odd or eccentric children and young people as psychiatrically ill or maladapted.

Although traditional researchers consider ASC as something that is "missing" in the individual, either as a biological deficit or a psychological impairment, this research has deliberately located ASC in the domain of "difference", rather than "disability". The study does not assume that autism is a "myth", nor that adjusting to the experience of having a child with ASC is not extremely difficult, but it seeks to shift the emphasis to people with ASC themselves. People with a diagnosis of ASC have a number of important views and ideas, which may prove invaluable for psychologists and other helping professionals. One of the main purposes of the research is to develop ideas of how mental health professionals can more usefully collaborate with young men diagnosed with ASC. It is hoped that investigating autobiographical accounts of people with autism can lead, as Harper (1999) has written, "to richer understanding and to just and socially responsible outcomes (p. 128)."

Data analysis

The data was subjected to "thematic" analysis, a term that describes a relatively simple process of coding, clustering codes to develop concepts or categories from the

coding, and developing themes from these concepts or categories that help to explain the phenomena under investigation. According to Coffey and Atkinson (1996), qualitative coding is primarily a way of interacting with and thinking about the data. A number of codes emerged with the thematic analysis of the data. The codes were grouped together through a process of dividing the data into units of meaning, thinking of the appropriate codes to represent each unit's meaning, and considering the relationship between thew codes and the data segment overall, together with how the codes might be meaningfully clustered together. After reading and re-reading the documents over a period of one year, a number of themes emerged from the data. Because the study is investigating a relatively neglected area of interest, this section concentrates on how the participants define the purpose of their writings on ASC and on their "everyday" experience of the condition.

The themes that emerged from the analysis included:
Understandings of the causes of autism, on a biochemical, structural, and functional level of explanation,
The experience of difference from others,
Uncertainty about the "unwritten rules" of society that dictated people's lives, and
The benefits of having an autism spectrum condition.

Although other clusters and themes emerged from the data, my interest in explanations of causation, and the benefits and challenges of ASC has meant that these themes are presented at this time. It is possible that further work can be generated based on themes that were not included in this study.

RESULTS AND DISCUSSION

The causes of autism

Autism as a biochemical and brain structure phenomenon

A number of authors presented the causes of autism as a phenomenon related to brain structures or biochemical processes.

Autism is caused by various biochemical processes which affect the way the brain develops. MS

For some time I believed that the brains of autistic people were structured slightly differently so that there is a greater tendency for neuronal impulses to travel up and down (literal thinking) and a lesser tendency for them to move sideways (lateral thinking). This phenomenon would be spread throughout the whole brain rather than being local to certain regions. MS

In these extracts, Marc describes autism as a "difference" in cognitive functioning, rather than a "disordered" phenomenon. As a result, Marc talks about the biological and cognitive functions with an impersonal stance, referring to "the brain" rather than "my brain". This strategy both enhances the authenticity of the scientific discourse by impersonalising the information and ascribing it to fact rather than opinion. It also serves to distance Marc from the "condition". In one account, Brad describes "how to understand people who are different", i.e. people with ASC.

Sometimes their brain is actually built differently or there is a short-circuit in the electrical pathways their brain uses to take in information and process it. So the pathways might not work the same as yours. BR

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Brad describes difference again, rather than disability. Yet, because autism is classified as a "mental disorder" of the central nervous system, requiring biochemical intervention, its clinical "symptoms" are interpreted as the psychological equivalents of underlying pathologies in the brain. According to Robert Spitzer, the chair of the DSM-III and DSM-IIIR work groups, a "mental disorder" exists as "merely a subset of medical disorder" (Spitzer & Endicott, 1978, p. 16), implying that psychopathology is best understood as a disease or illness entity manifesting as dysfunction within individuals. Intraorganismic dysfunction has been posited as the "core" of mental disorders, with social factors "providing a superficial overlay" (Thacker, Ward, & Strongman, 1999, p. 846). DSM's categorical "deficit" model of psychopathology has produced a medicalisation of human behaviour, in which symptoms often are stripped of their political, social, or evolutionary meanings. Therefore, autism is constructed as residing within the individual, its manifestation associated with a neurological dysfunction existing within the "patient".

Autism as information processing phenomenon

Another theme arising from the data is the information processing or cognitive model. In the following extracts, the authors describe autism as a cognitive distortion or a dysfunction in information processing.

I now feel that perhaps the root cause of autism is increased bias towards the reassessment of previous thoughts (hence the repetitions and rituals). Consequently the capacity for intuition and context awareness is reduced. MS

Some people don't process information the same way you do. Once information gets to your brain, your brain does things with it. I learned that when you see things, they usually remind you of other things, this is called association and train of thought. BR

Minshew and Goldstein (1998) found that people with ASC have specific cognitive profiles with normal performance on tasks requiring rote, mechanical, or perceptual processes, and poor performance on tasks requiring higher-order conceptual processes, reasoning, interpretation, integration, or abstraction. However, there is substantial variability in the intellectual profiles of people with autism and AS, and no cognitive pattern confirms or excludes a diagnosis of autism (Manjiviona & Prior, 1999). Similarly, there are many variations in how people with ASC describe the reasons for the difference, yet it is consistently described in non-pejorative terms, undermining the professional belief that ASC is, necessarily, a disability. The reports of the authors imply that it is perhaps those without autism who experience a disability, one in which tolerance for cognitive difference is not permitted.

Autism as a theory of mind phenomenon

Over the past fifteen years, researchers have investigated how people with autism explain and predict human behaviour. There are a number of words to describe this uniquely human ability, including theory of mind (Premack and Woodruff, 1978), folk psychology (Astington, 1994), and the intentional stance (Dennett, 1987). Folk psychology is the ability to attribute beliefs and thoughts to others, and to understand that others have mentalistic perspectives which are unique and different from our own (Leslie, 1987). Happe & Frith (1995) referred to theory of mind as the capacity to "mind-read", that is the ability that human beings have to interpret their own and others' behaviour in terms of what they know and feel. There is growing evidence

that many individuals with AS struggle to understand that other people have their own plans, thoughts, and points of view, and that they have difficulty understanding other people's beliefs, attitudes, and emotions. (Baron-Cohen, 2000).

According to the researchers, we are supposed to be weak on Theory of Mind, that is to say we cannot put ourselves in the position of others to know what they are thinking, and so supposedly lack empathy. How this relates to me is that I am never sure of how I am being understood in conversation or how to modify what I am doing to maximum effect in social relations. LA

Although the individual with ASC may be able to correctly describe other people's intentions, emotions, and conventions, Hobson (1993) has written that they are unable to execute this knowledge in a spontaneous and useful manner. The lack of spontaneous adaptation is associated with an over-reliance on formalistic rules of behavior. Gillberg (1995) has described this as a "disorder of empathy", the inability to effectively "read" others' needs and perspectives and respond appropriately. As a result, children with ASC tend to misread social situations and their interactions and responses are frequently viewed by others as "odd".

Some people who are different don't interact with people in the right ways. Figuring out right times and wrong times, and right places and wrong places, can be hard because there are not always clear rules. Almost everything I do is because I learned it. I don't really understand why people do things, why they laugh or get mad or wave their hands around or change their tone of voice, or how they know when to do those things, or what I should do back, unless I learned that exact situation. BR

Unwritten rules of society

By not understanding that other people think differently than themselves, or the "unwritten rules of society", many people with autism experience problems relating socially and communicating to other people, that is, they may not be able to anticipate what others will say or do in various situations. In addition, they may have difficulty understanding that their peers or classmates even have thoughts and emotions, and may thus appear to be self-centered, eccentric, or uncaring, although there is nothing to imply that autistic individuals feel superior to others (Klin & Volkmar, 2000).

When people disobey these unwritten rules, sometimes they get away with it, but usually they who break informal rules are made to suffer informal punishments. These punishments may include being laughed at, being treated as a less important person or being isolated. MS

This extract elegantly describes the powerful forces of conformity in society. It is possible to draw a link between the policing of the "unwritten rules" and the normalizing judgement of contemporary mental health care strategies, which presume that the most efficient form of guiding conduct is the capacity for self-government.

The most difficult thing about being autistic (or having Asperger syndrome) is that so many people expect you to know these rules and live by them, even though no-one has told you what these rules are. MS

Howlin (1998) has argued that the defining characteristic of persons with AS or autism is that their behaviour is rule-governed.

Whenever we go into a completely new environment and no-one knows us yet, we start off with an undamaged reputation, that is a clean slate. It is largely by breaking the unwritten rules of society that people dirty their slates.   MS

Some people who are different don't interact with people in the right ways. Figuring out right times and wrong times, and right places and wrong places, can be hard because there are not always clear rules.   KJP

Most children with AS, at least once they get to school age, are aware of other people, and express a desire to fit in socially and have friends, yet few individuals with ASC are able to form friendships (Filipek et al, 1999). They are often deeply frustrated and disappointed by their social difficulties. Their problem is not a lack of interaction so much as a lack of effectiveness in interactions, seeming to have difficulty knowing how to "make connections" socially. Because their approaches tend to be inappropriate and peculiar, they are often (involuntarily) socially isolated from their peers (Attwood, 1999).

Some people like to stand out. People who stand out but who cannot keep to the unwritten rules whilst doing so can very easily make themselves into a target for other peoples teasing or neglect.   MS

Yet, there is also resistance to these discourses and people with ASC who post their lives on the Internet are taking risks, risks of being laughed at, ridiculed, and treated as a "less important person."

Michel Foucault (1983) traced how the practices of psychology and psychiatry were instrumental in denying the voice of the mad by constructing their behaviour in the language of "mental illness". Discourses of mental health care construct the individual as an autonomous integrated self, striving for personal fulfillment, and

managing his or her life responsibly as an "active consumer". If one understands power in modern societies as "essentially oriented to the production of regimented, isolated and self-policing subjects" (Dews, 1984, p.77), then the control of the population is not through coercive social control, but through less visible strategies of normalization. For example, psychological norms and values implicit in studying autism have shaped the ways in which social authorities conceive of persons with ASC, their health and illness, and what is normal and what is pathological.

When you have read this book, you might think that these are the rules to a rather silly game, but the game is life and the rules cannot be changed. MS

The benefits of ASC

Despite the threat of an overarching tendency to conformity and "normality", a number of texts described positive benefits of living with ASC.

Having not been bound all your life by the unwritten rules of society may have made you a highly original thinker. MS

At the same time, I would like to keep my musical and artistic talent, and *myself*, though I'm not sure if *myself* is Asperger's or just affected by the symptoms of it. PS

But some people who are different have minds which are much quieter and not as busy and sensitive nerves, so they can hear these signals and they have room to let these signals in, and these signals are interesting enough to catch their attention, and simple enough to process. BR

If I didn't have Asperger's Syndrome it is unlikely that I would have had calendar calculating skills. If I didn't have Asperger's Syndrome it is unlikely I would have been fanatical and obsessional in some of my interests like I am which makes me want to look things up in detail. If I didn't have Asperger's Syndrome I may not have had a good memory for some things like I have. If I didn't have Asperger's Syndrome I may have been going round smashing phone boxes, nicking cars and beating old women up. And if I didn't have Asperger's Syndrome it is unlikely I would have designed this Website. KJP

IMPLICATIONS

The research has pointed out some possibilities for health professionals working with people with ASC. First of all, it is important to state that this report can not adequately represent the experience of the men who have written the accounts. Nor did it set out to do so. It is best is that professionals read the accounts for themselves, and to make them available to their clients with ASC. Using the personal accounts might provide the sort of self-help or homework that can be used in therapy. What the research can do is provide some thematic areas for development in the future, by attempting to make the information (initially at least) more manageable. If more information is available to professionals about the subjective life experience of a clinical population, then those professionals might just target sensitive interventions to those people.

Clinical psychology holds a privileged position in the field of autism and ASC. Only clinical psychologists and specialist medical practitioners (pediatricians and child psychiatrists) have the qualifications to diagnose ASC, thus providing educational funding where and when needed (Delaney, 2000, personal communication). One of the results of the diagnostic confusion has been a poor development of services, because without a label there is usually no service. One of the advantages of diagnosis is that people then know where to find appropriate services. This research project supports an ongoing tension between the benefits of accurate diagnosis and the dangers inherent in pathologising people's lives.

There is very little research into therapy with adults (and particularly men) with ASC or autism. The reason for this may be that they do not tend to self-present to therapists, except at the behest of their spouse or parent. If people have been diagnosed with ASC, the label of pervasive developmental disorder may inhibit individuals from seeking psychological assistance, with a view to "curing" the condition. One implication of this study is to encourage others to pursue research into psychotherapy process and outcomes for people with ASC.

Early diagnosis and appropriate intervention appears to hold the key to improved quality of life among adults with ASC, as support can be put into place for the child, both educationally and psychologically, as well as through programs to provide short and long-term support for the family. Yet we know that this is not the norm. Gillberg (1998) has estimated that perhaps 30-50% of all adults with ASC are never evaluated or correctly diagnosed. This is less of a concern except that the loneliness and yearning for others can isolate the person from others, and can provide opportunities for self-blame and despair. These "normal Aspergers" are viewed by others as "just different" or eccentric, or they may be diagnosed with other psychiatric disorders (Perlman, 2000). Tantum (2000) made a plea that some of these highest functioning and brightest individuals with ASC represent a unique resource for society, having the single mindedness and consuming interest to advance our knowledge in various areas such as science, music, mathematics, and engineering.

The diagnosis of ASC is profoundly influenced by matters of policy and clinical judgment. Autism spectrum conditions represent a challenge to the concept of "disorder" in psychiatry. In conclusion, a diagnosis of ASC may provide a "powerful

interpretation of a [person's] unusual behaviour, but a label should not be considered an explanation and given more status than it deserves" (Szatmari, 1998, p. 74).

Strengths

Unlike most "illness narratives", which occur in institutional or clinical contexts and in elicited contexts, this research uses narratives that occur in everyday contexts. If one considers that the goal of everyday contextual narratives is to communicate and negotiate the world of illness, then this study has as its strength the depiction of illness in a socially understandable manner.

The study fulfils a number of criteria for conducting psychological research. First of all, it is relevant. The growing population of web pages created by young men with ASC represents one outlet for the burgeoning information available on autism, from the mass media to peer-reviewed journals. The information on these pages could provide understandings about ASC and autism for those who choose to work with them. Secondly, the first-person perspective may build links with the third-person studies that have dominated the research terrain. Thirdly, it is credible, in that the enquiry was carried out in a way which ensures that the research topic was accurately identified and described. The geographical spread of personal accounts means the findings may also be applicable across different countries and settings.

Limitations

There are at least three significant limitations to the study:

1) Because a convenience sample was researched, the participants were not a random sample nor representative of the overall ASC population, and the results of the study may not be generalisable to all young men with ASC. For example, it is recognised that people using the Internet may be "skewed toward the high end of the socioeconomic and educational spectrum" (Riva and Galimberti, 2001, p. 3).

2) Because the study participants in Internet research were unmonitored, it is impossible to be sure about the information collected. Although the interview participants were "screened" about the manner and place of diagnosis, the difficulty in making the diagnosis renders it possible that some participants are not "true" cases of ASC.

3) Because the source of material was written, it is very difficult to explore areas of language use that rely on face to face interaction. These include prosody, echolalia, peculiar voice characteristics (such as intonation and inflection), and difficulties with appreciating humour and sarcasm. Whether an individual has difficulty initiating or sustaining a conversation is also impossible to discover. As is the subjects' ability to understand complex meanings. Nonverbal communication elements, such as facial and gestural expressions, are also absent from the analysis.

Future research

In conclusion, there are a number of possible avenues for future research. Because of the affinity for computers that most people with ASC possess, professionals could

facilitate the development of Internet-based resources where people with ASC can be encouraged to interact with each other via the computer. By participating in such an exchange people with ASC can share information and develop skills in self-advocacy and social practice that can be of tangible benefit in their lives. There are many opportunities for people with ASC to discuss and debate their experiences, such as chat rooms and list servers. Future research could explore the use of e-mail communication in psychotherapy. For example, it may be possible to design an Internet based study to evaluate the outcome of psychotherapy with individuals with ASC. Further exploration of what people with ASC are telling professionals about their support needs would be of value to both parties. Research needs to grasp the services that would best meet the needs of adolescents and adults diagnosed with ASC.

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APPENDIX I

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