

Counselling people labelled with asperger syndrome

HODGE, Nick <<http://orcid.org/0000-0001-5706-1865>>

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/6259/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

HODGE, Nick (2012). Counselling people labelled with asperger syndrome. In: FELTHAM, Colin and HORTON, Ian, (eds.) The SAGE handbook of counselling and psychotherapy. London, SAGE, 554-558.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Counselling people with Asperger Syndrome

Nick Hodge

Defining and recognising Asperger Syndrome

Asperger Syndrome (AS) is the diagnosis given to people who have modes of thinking and experiencing that result in profound and fundamental difficulties with negotiating the neurotypical social world. Neurotypical (NT) and predominant neurotype (PNT) are terms that are used by many people with AS to describe those who have what is generally considered as a more 'typical' system of social thinking and understanding. Asperger Syndrome is one of the 'conditions' that come within the umbrella title of the autism spectrum. Whether Asperger Syndrome is distinct from 'High Functioning Autism' (HFA) is contested; some argue that the two conditions differ in that people with AS desire friendship but cannot identify nor apply the necessary social processes to achieve this whereas people with HFA are usually emotionally unconcerned by social isolation. Whilst the causes of AS have not been specifically identified they are accepted as being organic in origin: AS results from physiology and not from developmental experience. It is a lifelong way of being that is different but not lesser and it is not something that can or should be 'cured'.

Estimates of incidence of AS vary widely but if a conservative figure of 1: 200 is used then the population of people who have AS in the UK will be at least 300,000.

Although it still appears that significantly more males than females have AS this is partly due to under recognition of the syndrome in women. There is no medical test for AS: it is diagnosed by observation of behaviour and accounts of experience. AS is evidenced by pervasive, fundamental and ongoing differences (compared with the

predominant neurotype) in three categories: social communication, social interaction and flexibility of thinking, sometimes referred to as social imagination. AS can make it highly problematic to understand oneself; also problematic can be managing or recognising one's emotions and those of others; understanding and employing PNT social rules and etiquette; being able to predict or monitor how others might react to social exchanges; identifying, and fitting in with, social and cultural trends that differ from one's own. Other common characteristics include having very strong but narrow and dominating interests and unusual sensory experiences that can make environments highly challenging and stressful. However, people are of course individuals with their own distinct profile of interests, abilities and challenges. Ways of experiencing the world are rich and varied and it should not be assumed that all people with AS will have a prescribed set of concerns or will demonstrate similar responses to counselling approaches.

People with AS are likely to have average or above average intellectual abilities and they are often articulate. These strengths can mask the extent of the difficulties that they experience. As a result, people with AS may not receive a diagnosis until well into adulthood and frequently not at all. They may arrive at counselling because of years of being bullied and ostracised for being perceived as 'different'; trying to manage environments that are overwhelmingly stressful; and/or because partners are seeking help with managing the lack of empathy, comfort and appreciation within the relationship. So significant are the tensions of trying to exist in a socially orientated world that these are often demonstrated in people with AS through forms such as extreme anxiety and depression. Other associated conditions include eating disorders, substance abuse and bipolar disorder.

Clients may not have a diagnosis of AS at the time of seeing a counsellor or may not disclose it. Indeed, many counsellors will have encountered Asperger Syndrome without either the counsellor or the client realising it. For those who have acquired a diagnosis, identifying to others as having AS is something that is often tightly controlled by individuals who have internalised a view of Asperger Syndrome as a negative and lesser way of being and/or who fear how association with this label might impact on how others perceive and respond to them. Clients are likely to have established different positions in relation to this, from embracing and promoting the label to trying to 'pass' as neurotypical. Counsellors, therefore, may need to recognise the AS modes of thinking and experiencing from how a client expresses his or her life account. Likely signposts will include a profound lack of understanding of others and feelings of marginalisation: people with AS may well express a need to belong but will be employing strategies to engage that encounter constant rejection from others, the reasons for which often seem inexplicable to the client. Some clients with AS will experience fundamental difficulty with reflecting on their own behaviour, emotions and feelings, in a way that makes sense to a counsellor who is neurotypical. A further signpost may be that the client does not use a typical range of body and facial gestures: counsellors may find it harder to 'read' the client with AS or may feel that their own gestural communications are not being responded to.

Barriers to accessing counselling

People with AS may well experience a number of barriers to accessing counselling services. Generally they will have fewer financial resources than those who are non disabled and so the cost of counselling is frequently prohibitive (Reeve, 2000).

Professionals or carers may assume that anxiety and depression are characteristic

of the syndrome, rather than a response to stressful environments, and so not support people with AS in accessing counselling services.

Additional barriers for people with AS may include their lack of awareness of the availability and purpose of counselling; a perspective that the problem always lies 'out there' in society and it is that which needs to change rather than the individual with AS; fear of revealing oneself as having AS; and difficulty with practical and organisational processes such as locating a counsellor, making an appointment and finding a venue (Tantam, 2003). Counsellors' perceptions of their own competence can also lead them to reject potential clients because they have a label signifying a 'condition' that the counsellor feels needs specialist help (Raffensperger, 2009). Unfortunately there are very few specialist services available and so this position can then leave people with AS without any access to counselling services.

There are a number of strategies that counsellors can employ to help to remove some of these barriers. These include promoting their services through AS support networks; identifying potential sources of funding; reporting on how counselling has supported clients with AS and being flexible about where sessions might take place and in what form. Counsellors should also consider working, where it seems in the best interests of the client and/or the counsellor, as part of a team with a supporter who knows the client well. This raises ethical issues for counsellors including confidentiality and client consent but research has shown that this type of team working is likely to make a positive contribution to counselling outcomes for people with AS (Raffensperger, 2009).

Effective approaches

There have been relatively few research studies and accounts of counselling related interventions with clients who have AS. To date there is no definitive study that establishes either the general effectiveness of counselling for people with AS or the primacy of any particular approach. Many people with AS are themselves dismissive of psychotherapy, viewing their difficulties with social understanding and engagement as being the result of how they are 'wired' rather than having a psychological causation rooted in their past (Singer, 1999). However, psychotherapy might have something to offer people with AS if it uses their strengths with logical and systematic thinking to identify and understand how environments and relationships with others might have disabled and disempowered them; psychotherapy, if based upon an acceptance of the nature of autistic development, does have the potential to help people with AS to return to the authentic Asperger self.

More claims are made within the research literature and practice accounts for the effectiveness of programmes such as cognitive behaviour therapy and solution focused therapy that are carried out 'in the context of solving real problems in everyday life' (Tantam and Girgis, 2009:56) and which 'address the situations about which the person with AS is concerned, however idiosyncratic those concerns might be to others' (Tantam, 2003: 157). The literature suggests that these more directive counselling approaches, for people with AS, should include explicit guidance on how to manage social situations and emotions. Attwood (2004) in particular suggests a number of useful, practical and accessible strategies that can support people with AS by presenting abstract concepts in more visual, concrete forms. Information that

is written down is often much more accessible to people with AS as text can be referred to, and processed, over time. These strategies focus on enabling people with AS to identify and understand their emotions and to find new ways of behaving that might achieve their goals more effectively. Examples of these include using social stories (Gray, 2001) that give explicit written advice on how to manage situations which a client can then use repeatedly to rehearse situations. Social Skills training sessions can be useful but social engagement is spontaneous and fluid and it is difficult to prepare someone for all eventualities. It is often more helpful to support a client with formulating practical strategies for managing breakdowns in communication. These might include identifying whom to go to for guidance or using a phrase to 'buy processing time', such as 'let me think about that and I will get back to you'. Selecting appropriate forms of support will depend upon a counsellor being able to understand the client's 'subjective experience of Asperger syndrome' (Tantam, 2000: 61) and to position this in relation to the person's capacity for empathy and reflection. Psychological 'disorder' caused by unwanted isolation; lack of meaningful occupation; living on benefits; being subject to victimisation now and/or in the past, may not be easily resolved unless there is a realistic chance of improving the underlying environmental factors.

Impairment and Disability attract a wide range of 'therapies' and/or 'interventions' that are professionally packaged and often sold as 'the cure' or 'the answer' to the 'problem'. Although some might be well intentioned, such approaches are usually expensive to access and not supported by any reliable body of empirical research. Swimming with dolphins, for example, might well be a pleasurable and motivating activity for some but there is no reliable evidence to support some of the more

spurious claims that are associated with the practice. There are more reliable accounts available of the benefits to well being of pet ownership, horse riding and the use of animals as assistive supports within the community (Burrows, Adams and Spiers, 2008) but clients are likely to have definite perspectives on whether animals, for them, are sources of comfort, enablement or stress.

Counsellors may help the person with AS to identify and articulate the barriers to their personal well being but enabling solutions might well require the support of a team around the person with AS. Counsellors should not be discouraged from engaging with people with AS however if access to a support team is not immediately apparent. People with AS often experience a very limited number of positive relationships; the act of regular and predictable engagement with another person within a framework of clearly articulated rules and processes that enable being heard, feeling understood and being reminded of your skills and capabilities might go a long way to raising self esteem and improving quality of life.

Working with people with less typical modes of thinking, experiencing and engagement can challenge and enrich the practice of counselling. Counsellors may well be challenged to present themselves differently to meet the requirements of the client with AS. People with AS often rely upon clearly expressed expectations from others and the boundaries around particular relationships being made explicit. This is good counselling practice anyway but it may help to record this agreement, to make a visual account that the client can revisit, as required, until sure of what is expected and permitted. An assessment of the client's needs may also lead the counsellor to work with approaches that might feel outside of her/his immediate comfort zone, such as using technology in sessions (Abney and Maddux, 2004) or even conducting

the whole process over the internet (Barak, Klein and Proudfoot 2009): engagement via computers is reported frequently as especially suited the communicative and processing style of people with AS. Linking people with AS into internet support groups where they might be able to share interests and life management strategies and/or local support groups can also make significant differences to levels of well being.

Conclusion

Although there are no studies that definitively demonstrate the effectiveness of counselling for people with AS, the value of therapy as a general practice is now well established: there is no reason to think that these benefits would not apply equally to clients with AS. All effective counselling will depend on a detailed assessment of a person's world view and the adoption of an approach which will fit with this mode of being. For clients with AS a successful strategy is likely to be one that involves validating the experience of the client , identifying together his/her skills and abilities and then using these to develop a programme of change with a focus on problem solving within the real life context. The strategies adopted may also require a focus on changing disabling environments rather than the client. Counsellors may need to seek support for this process from those who know the client well and who might be able to work with him or her outside of the sessions. Outside organisations that can inform about AS will also be a useful resource. Counsellors may need to adapt their own style of communication and also engage with a wider range of approaches than they are used to; many such developments in their practice may well benefit all of a counsellor's clients, not just those with AS. Specialist counselling services for people with AS are rare and it would not be helpful if the lack of practical access to

these denies people with AS the benefits of counselling. The counsellor who embraces the challenge of working with clients who have AS is likely to find this an enriching and personally developing experience. The ability to identify, appreciate, learn about and accommodate different ways of being in the world is really the essential requirement for effective counselling with people with AS.

Resources

Specialist counselling services for people with Asperger Syndrome are extremely rare. One example is the Sheffield Asperger Syndrome Counselling Service (www.sct.nhs.uk/aspergersservice). There are also some individual specialist counsellors such as Maxine Aston (www.maxineaston.co.uk).

Attwood, T. (2007) *The Complete Guide to Asperger Syndrome*. London: Jessica Kingsley Publishers - an excellent introduction for anyone wanting to know more about AS.

Blomfield, R. (2010) *Doing Therapy with Children and Adolescents with Asperger Syndrome*. New Jersey: John Wiley & Sons, Inc. - uses case material to illustrate issues involved with doing talk and play therapy with young people with AS.

Paxton, K. and Estay, I.A. (2007) *Counselling people on the autism spectrum: a practical manual*. London: Jessica Kingsley Publishers - contains lots of practical advice, illustrated with examples from practice.

Thompson, B. (2008) *Asperger Counselling for Couples*. London: Jessica Kingsley Publishers - offers a 7 stage programme of support for counsellors and their clients.

There is also a useful information sheet by Maxine Aston for the BACP entitled G9 information sheet: Recognising AS and its implications for therapy.

AS community websites that can provide information and social and emotional support for people with AS include:

www.wrongplanet.net

www.aspergerinfo.com

Other useful information websites for people with AS and their supporters include:

www.nas.org.uk

www.tonyattwood.com.au

References

Abney, P.C. and Maddux, C.D. (2004) Counseling and technology: some thoughts about the controversy. *Journal of Technology in Human Services* 22 (3): 1-24.

Attwood, T. (2004) Cognitive behaviour therapy for children and adults with Asperger's syndrome. *Behaviour Change* 21 (3): 147-161.

Barak, A., Klein, B., Proudfoot, J.G. (2009) Defining internet-supported therapeutic interventions. *Annals of Behavioural Medicine* 38: 4-17.

Burrows, K.E., Adams, C. and Spiers, J. (2008) Sentinels of Safety: service dogs ensure safety and enhance well-being for families with autistic children. *Qualitative Health Research* 18 (12): 1642 - 1649.

Gray, C. (2001) *The new social story book*. Arlington: Future Horizons Inc.

Raffensperger, M (2009) Factors that influence outcomes for clients with an intellectual disability. *British Journal of Guidance & Counselling* 37 (4): 495-509.

Reeve, D. (2000) Oppression within the counselling room. *Disability & Society* 15 (4): 669-682.

Singer, J. (1999) 'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference' in M. Corker and S. French (Eds) *Disability Discourse*. Buckingham: Open University Press.

Tantam, D. (2000) Psychological disorder in adolescents and adults with Asperger Syndrome. *Autism* 4 (1): 47-62.

Tantam, D. (2003) The challenge of adolescents and adults with Asperger syndrome. *Child and adolescent psychiatric clinics of North America* 12: 143-163.

Tantam, D. and Girgis, S. (2009) Recognition and treatment of Asperger Syndrome in the community. *British Medical Bulletin* 89: 41-62.

Acknowledgements

Thank you to Luke Beardon and Katherine Runswick-Cole for comments on the draft version of this chapter.