

Psychiatric services for adolescents and adults with Asperger syndrome and other autistic-spectrum disorders

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Executive summary and recommendations

Autistic-spectrum disorders are a complex group of developmental disorders. They often require psychiatric involvement in their diagnosis, particularly as they are associated with a high frequency of comorbid psychiatric disorder, colouring their presentation and complicating their management. Autistic-spectrum disorders present over a wide range of age and ability, which means that they need to be addressed by all psychiatric specialties.

This report presents a consensus view about the psychiatric services that are required in adolescence and adulthood for individuals with autistic-spectrum disorders, and although the focus is often on diagnosis, this is only one part of a wider process of multidisciplinary assessment that should then flow on to management. It also recognises that the psychiatric service is only one component of the wider provision required by this group of individuals to achieve parity with the rest of the population. The development of this wider, multi-agency group of services is the subject of proposed strategies by the National Autistic Society as well as of Health and Social Service planning in Wales, Scotland and Northern Ireland.

After a description of the syndrome, its comorbidity and epidemiology, this report distinguishes diagnosis from broader, multidisciplinary assessment. Reviewing the methodology and difficulties of the diagnostic process, it concludes that all psychiatrists should be able to recognise the syndrome, diagnosing it in clear-cut cases, and be aware of its implications. This needs to be the subject of postgraduate training at all levels, from basic psychiatric training through to continuing professional development.

Besides a shortfall in services specific to this population, they are poorly served by most standard services. Particularly deprived are those individuals with autistic-spectrum disorders who are too old for adolescent services and too able for learning disability services, thereby finding themselves barred from the services that are most familiar with the issues linked with developmental disorder and dependency on carers. Psychiatric provision needs to bridge this gap with a combination of training, better liaison between its specialties and the development of specialist interest and tertiary services. It needs to work in conjunction with both the statutory and the independent sectors in ensuring adequate psychiatric input into autism-specific services. As psychiatric services are overstretched by existing demands, any improvement requires service commissioners to recognise the shortfall, encourage such changes as might reduce it and specifically support further developments.

For those cases where diagnosis is less straightforward, or where clinical management is more complex, there needs to be access to local specialist expertise and, where necessary, to tertiary specialist services. This applies particularly to the provision for psychiatric admission, whether as day patients or in-patients, as this group of people may well find the

usual clinical environ distressing and unhelpful. This can be because of an intrusive peer group, a day that is insufficiently structured or predictable, or an overstimulating setting.

RECOMMENDATIONS

- 1 The views of individuals with autistic-spectrum disorders should be incorporated routinely in service planning both individually and collectively.
- 2 Diagnosis should be only one part of a multidisciplinary assessment that might include cognitive, educational, occupational, social and communicative abilities as well as any other systems (for example, motor or sensory) that are relevant to its purpose. It needs to take account of the language and cultural background of the individual and their family.
- 3 The conclusions from such a clinical assessment should be fed back as written reports and minutes to avert the misunderstandings that arise from oral communication. Diagnosis should only be undertaken in the context of counselling concerning the implications of the diagnosis and how the information should be shared.
- 4 Transition planning should recognise that not all young people with an autistic-spectrum disorder will need to make use of adult services, but for those who do there should be a smooth link between services that passes on information about why and how the disorder was diagnosed together with its implications. Many agencies routinely destroy information about young people after a set period and arrangements should be made to ensure that this crucial information is not lost; a copy might be given to the individual with the disorder or their carer. It should be recognised that those who are moving out of psychiatric services will still require additional support whether they are moving on to education or employment and this should also be the focus of multi-agency planning.
- 5 Commissioners should ensure that there is access to local, basic diagnostic expertise that would allow for the firm diagnosis of autistic-spectrum disorders in clear-cut cases. They should also ensure access to a second level of diagnostic expertise for those individuals where there is diagnostic uncertainty.
- 6 Services should be well integrated so that clinical diagnosis is not isolated from treatment and that this, in turn, is closely linked to the (non-psychiatric) services that are provided by other agencies.
- 7 Psychiatric training should include experience in the diagnosis, assessment and management of individuals with autistic-spectrum disorders. In particular, there should be some supervised experience with adolescents and adults of normal cognitive ability who have these disorders.
- 8 For those individuals with autistic-spectrum disorders who become involved in legal processes, there should be routine access to psychiatric services that can:
 - (a) distinguish autistic-spectrum disorders from other psychiatric

- disorders and, in particular, from the personality disorders as well as other neuropsychiatric disorders and learning disability
- (b) recognise the potential impact of these disorders on responsibility, mental capacity, fitness to plead and the ability to bear witness
 - (c) encourage awareness of, and provision for, autistic-spectrum disorders in court processes and in subsequent care
 - (d) develop appropriate interventions and therapies within secure and forensic settings.
- 9 Commissioners should ensure that individuals who are thought to have autistic-spectrum disorders have access to expertise across a broad range of therapeutic approaches, including those relevant to the psychological management of these specific disorders, delivered through autism-friendly treatment facilities that include the whole range of age and ability and take into account cultural factors.
- 10 Referrals should be made within a formal contractual programme (rather than on an individual basis) to ensure that the provider (rather than any individual clinician) accepts responsibility for the care of the individual with the disorder and there should be regional agreement as to the roles of various individual consultants. It should not be assumed that a service could absorb this patient group without specific planning and investment.
- 11 As services for those of working age are often poorly developed, it would be helpful if an 'autistic-spectrum disorders champion' were identified within each strategic health authority area. This would be a senior clinician with experience of the psychological management of autistic-spectrum disorders, who have a specific responsibility for advising on treatment options outside of child and adolescent mental health services.
- 12 Research should be encouraged into the impact of autistic-spectrum disorders on adolescence and adulthood as it affects clinical psychiatry.

Introduction

PURPOSE OF THE REPORT

This report addresses the psychiatric services that might be offered to adolescents (taken as being from puberty up to 18th birthday) and adults (from 18th birthday) with autistic-spectrum disorders, a category that includes individuals with Asperger syndrome as well as with autism. The report focuses narrowly on psychiatry, although recognises that this is only one part of a much wider range of services (Powell, 2002). It is a preliminary exercise, intended to inform the broader, multidisciplinary and multi-agency approaches that are under way. Although this is about a specific form of developmental disorder, it should be recognised that there are other, overlapping subgroups (such as those with attention-deficit disorder, language disorders, dyspraxia or personality disorder) with similar symptomatology that may have very similar needs.

The report is addressed to psychiatrists, stakeholders in the development of autistic-spectrum disorders services and commissioners of adolescent and adult services, across all the psychiatric specialties.

‘I owe far more to the consultant psychiatrist who suspected that I had Asperger’s syndrome than I do to all the other psychiatrists who suggested clever drugs to manage my depression’
(Anonymous, quoted in *British Medical Journal Career Focus*, 2004)

THE DISORDER

TERMINOLOGY

Autistic-spectrum disorders represent a subset of the pervasive developmental disorders, a group of lifelong disorders characterised by their effect on social and communication skills as well as by a restricted, stereotyped, repetitive repertoire of interests and activities. It takes a variety of forms that are expressed with different intensity, giving a spectrum that runs from clear-cut autism through to subtle variants that shade into traits found within the normal (‘neurotypical’) population. The term autistic-spectrum disorders has been selected because, although autism itself is well validated and defined by ICD-10 (World Health Organization, 1993) and DSM-IV-TR (American Psychiatric Association, 2000), there is much more uncertainty about the validity of, and distinctions between, allied disorders such as Asperger syndrome and pervasive developmental disorder – not

otherwise specified. The needs of those who, in addition to autistic-spectrum disorders, have a significant intellectual disability have become relatively well recognised within the more generic services for learning disability. On the other hand, there is more ambiguity as to how services should be provided for those individuals at the more able end of the spectrum, often with good syntactical speech (but with more subtle communication deficits), who are included in such concepts as 'high-functioning autism' and 'Asperger syndrome'. Consequently there is an emphasis on their difficulties and needs in this report.

ALERTING CHARACTERISTICS

Autistic-spectrum disorders are complex, affecting a wide range of physiological systems and presenting in a variety of ways. The following signs should make the clinician think of its possibility and look for further evidence:

- Difficulties with social relationships (i.e. social isolation):
 - few or no sustained relationships; those that exist are likely to be either distant or intense
 - persistent aloofness or awkward interaction with peers (which sometimes may be unduly compliant or passive)
 - unusually egocentric with little concern for others or awareness of their viewpoint and limited empathy or sensitivity
 - lack of awareness of social rules; prone to social blunders.
- Problems in communication:
 - odd voice, monotonous and perhaps at an unusual volume
 - talking at (rather than to) you with little awareness of your response
 - language is superficially good but too formal, stilted or pedantic and with difficulty in catching any meaning other than the literal
 - rather wooden, impassive appearance with few gestures and a rather odd, poorly coordinated gaze that may either avoid looking at you or else look through you and can be misinterpreted as furtive or aggressive respectively (i.e. limited nonverbal communicative behaviour)
 - awkward or odd posture and body language.
- Absorbing and narrow interests:
 - obsessively pursued interests
 - unusually circumscribed interests that contribute little to a wider life (for example, collecting facts and objects that have limited practical or social value)
 - a set approach to everyday life that may include unusual routines or rituals; change is often upsetting.
- A disorder that, although its presentation may change and moderate with age, has a childhood onset and is lifelong.

The great variation in form and intensity means that stereotypes can be misleading. In particular, as the presentation can be obscured by developmental change and successful compensation for disabilities, autistic-spectrum disorders may only be revealed by the early developmental history.

COMORBIDITY

Autism-spectrum disorders are associated with a wide variety of comorbid psychiatric conditions (for example, depression, anxiety, bipolar and obsessive-compulsive disorders) as well as with other developmental disorders, notably attention-deficit and tic disorders and epilepsy. Its core is a constellation of particular developmental disabilities and linked to this there may be others (such as dyspraxia) together with impairments of elements of higher cognition that range from perception to executive function. Autistic-spectrum disorders can therefore both colour the presentation of a comorbid psychiatric disorder and affect its management.

The combination of limited social protective factors with, for example, poor self-help and independence skills, a reduced ability to gain employment and difficulty in making intimate adult relationships, leaves the individual more open to mental health and social problems such as marital disharmony and breakdown. Similarly, a number of factors may predispose the individual to offending. For example, unusual behaviour that appears risky, threatening or potentially dangerous will bring an individual to the attention of the police and other services whose response may misinterpret the individual's level of anxiety or other aspects of their disorder. Autistic-spectrum disorders may affect levels of responsibility, ability to be interviewed, to bear witness and to be tried. All this is compounded because the characteristics of these disorders can make it difficult for the individual to recognise or to acknowledge their own disabilities and therefore to obtain help.

Treatment requires a flexible approach from a multi-agency/multi-disciplinary synthesis of services that is sufficiently comprehensive to be capable of encompassing their range of complex needs. The breadth of issues that arise, across the whole range of age and ability, mean that the individual may need to draw on any of the range of psychiatric services and specialties.

EPIDEMIOLOGY

Although 80% of individuals with childhood autism (ICD-10 F84.0) have a significant general intellectual disability, about 80% of the population with autistic-spectrum disorders are of (at least) normal intellectual ability. There has been a shift in our perception from a disorder that falls within a discrete and narrow category to one that is less well demarcated and is more widespread. Several studies indicate the prevalence of autistic-spectrum disorders in childhood and adolescence to be at least ten times greater than previously thought, with estimates ranging from 60 to 90 people per 10000 (levels that approach those of schizophrenia) (Fombonne, 2003; Green *et al*, 2005). There is an increased prevalence in migrants that may partially explain why it should be particularly common in an African-Caribbean population (Goodman & Richards, 1995; Dyches *et al*, 2004). However, ethnic factors may not only delay engagement in the diagnostic process but also prolong the time taken for the diagnosis to be made (Mandell *et al*, 2002).

Although most research on autistic-spectrum disorders has focused on children, the lifelong nature of the disorder would suggest that there are many more affected adults. Its apparent prevalence might be reduced by the tendency of core autistic symptoms to improve over time, possibly becoming subclinical and only emerging in an adverse environment or crisis that causes the individual to decompensate. This is not to say that there is an even

improvement of all symptoms; in particular, a selective improvement in social impairment can result in someone who falls below the diagnostic threshold but continues to have a number of disabilities in perception, cognition and communication. This can be all the more handicapping because the person now is less obviously disabled. Most individuals continue to be dependent on the support of others and, although the presence of intellectual disability is a crucial factor (Lord & Bailey, 2002), normal ability does not necessarily bring a favourable outcome, as only about 16% of individuals become fully independent (Howlin *et al*, 2000; Engstrom *et al*, 2003; Fombonne, 2003).

Poor outcome is associated particularly with the development of comorbid psychiatric problems in late adolescence and/or early adulthood, frequently accompanied by an overall deterioration in functioning (Ballaban-Gil *et al*, 1996; Hutton, 1998; Billstedt *et al*, 2005). The prevalence of psychiatric disorders (including severe anxiety, depression, other psychoses, single psychotic episodes, catatonia, obsessive-compulsive disorder, phobia, and self-injury) is variable, ranging from 16% to 35%, but is consistently far higher than estimated for the general population (Bebbington *et al*, 1997; Brugha *et al*, 2001). In a large survey, parents of adults with Asperger syndrome reported that a third of their children had experienced mental ill health, and over half of these had had depression (Barnard *et al*, 2001). It also drew attention to the adverse impact the disorder had on the family, particularly where diagnosis had been delayed (Barnard *et al*, 2001). Despite the impact of mental health problems, there have been no large-scale systematic studies either of the frequency of psychiatric disturbance in adults with autistic-spectrum disorders or of the frequency of autistic-spectrum disorders in those in contact with mental health services. Although these disorders are relatively uncommon, their association with comorbid psychiatric disorder will increase their prevalence in the clinic, where, overshadowed by the comorbidity, they may go unrecognised. In people with learning disability, autistic-spectrum disorders are frequent; the more autistic traits present, the greater the degree of disability and disturbed behaviour (Bhaumik *et al*, 1997).

The majority of individuals with autistic-spectrum disorders are law-abiding and even rule-bound but there is a debate as to the extent to which the characteristics of these disorders may predispose to entanglement with the law (Barry-Walsh & Mullen, 2004). It would be unwise to infer that, simply because there is little in the published literature, the person with autistic-spectrum disorders does not offend. Two studies of special hospitals have indicated an increased prevalence of autistic-spectrum disorders (Scragg & Shah, 1994; Hare *et al*, 2000), but their specialist nature prohibits extrapolation to other hospitals or prisons. A recent study of Scottish institutions highlights the difficulty in identifying individuals, let alone estimating prevalence (Scottish Executive, 2004). There are no systematic community studies and our perception is limited to a slowly growing number of reports in the professional literature coupled with the small number of cases that have received extensive media coverage.

POLICY

Increasing recognition of the prevalence of autistic-spectrum disorders and of its associated problems, and particularly of Asperger syndrome, has led to a demand for services, both for diagnosis and for management. In 2002

the National Autistic Society produced good practice guidelines for services for adults with Asperger syndrome (Powell, 2002) that identified many areas of shortfall and made recommendations for meeting them. After the development of the National Autism Plan for Children (Le Couteur, 2003) the National Autistic Society carried out a consultation exercise and the results were used to formulate a proposal for a similar convention for older adolescents and adults.

Autistic-spectrum disorders are not an illness but a disability that can have a major impact on the development, presentation and management of psychiatric disturbance. In principle, disability should not bar anyone from access to all medical services, including psychiatric services, but a number of individuals will need these to be buttressed by specialist services. The majority of individuals with these disorders are of normal intellectual ability even though the effect of the disorder may be to reduce their functional ability to cope with everyday life and to make them dependent on long-term support. They fall into a limbo between the various psychiatric specialties, their ability putting them outside learning disability contracts but with developmental disabilities that, once they have outgrown child and adolescent services, may be unfamiliar to the various specialties dealing with adult mental health or else fall outside their remit. These issues are touched on in the Council report on services for individuals with mild or borderline learning disability (Royal College of Psychiatrists, 2003). This report emphasised that the defining criterion for acceptance by the services provided by learning disability psychiatry should continue to be a measured overall intelligence quotient (IQ) of less than 70. At the same time it recognised that individuals with an autistic-spectrum disorder were a group who, at times, might be better served by learning disability services. It is recommended that individual cases should be approached flexibly and that there should be direct links between psychiatrists in learning disabilities and those in the other specialties, both for planning and in clinical liaison. It was left unresolved as to how the presence of autistic-spectrum disorders might affect the provision of in-patient and day-patient care or specialist areas such as psychotherapy or forensic provision.

In England, the report *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001a) acknowledges that autistic-spectrum disorders often pass unrecognised and noted the importance of adequate local provision for this group. While this report was concerned exclusively with individuals with generalised learning disability, the subsequent implementation guidance (Department of Health, 2001b) explicitly included individuals with Asperger syndrome, stating that they should have access to learning disability services where appropriate. The Department of Health has also defined Asperger syndrome as one of the disorders that requires specialist commissioning (Specialised Services National Definition Set: No. 22 Specialised Mental Health (Adult)). However, an earlier report, commissioned by the Department of Health (Holland *et al*, 2000), has been ignored and the relevant recommendations of the Reed report (Reed, 1992) have still to be implemented.

In Scotland, the needs of adults with autistic-spectrum disorders are recognised in *The Same as You?* (Scottish Executive, 2000), which emphasised early diagnosis and the adaptation and development of suitable services both as specialist services and as part of the mainstream. It recommended a national network, its function to be defined by a subsequent working party to be led by the Scottish Society for Autism in conjunction with the National Autistic Society. It set out machinery, through Partnerships

in Practice, by which local multi-agency groups could develop services. Prompted by the Needs Assessment Report (Public Health Institute of Scotland, 2001) that included both children and adults, it was subsequently confirmed that these recommendations should include all individuals with autistic-spectrum disorders irrespective of ability (Scottish Executive, 2003).

At the time of writing this report, the Welsh Assembly government was developing the All Wales Strategy for Autism that proposed to set out a comprehensive multi-agency approach for children, adolescents and adults, including education, health and social services, in conjunction with Autism Cymru, a voluntary agency. In addition to service provision, it would give recommendations on training and research.

The Northern Ireland Framework for Adult Mental Health (also in preparation at the time of writing) is likely to recognise the prevalence and comorbidity of autistic-spectrum disorders and to present a vision of increased professional awareness, clear pathways of support and service access and clinical interventions within a wider framework that will involve all agencies and take account of the needs of carers.

The strategy for mental health services in the Republic of Ireland acknowledged the need to make specialist provision where learning disability is accompanied by an autistic-spectrum disorder (Irish College of Psychiatrists, 2004) but does not provide for those of normal intellectual ability.

RECOMMENDATION

- 1 The views of individuals with autistic-spectrum disorders should be incorporated routinely in service planning both individually and collectively.

Diagnosis and assessment

HOW ARE AUTISTIC-SPECTRUM DISORDERS DIAGNOSED?

Clinical diagnosis is the allocation of a series of descriptive labels that summarise whether an individual meets the diagnostic criteria agreed by consensus and set out in such systems as ICD-10 and DSM-IV-TR. However, the criteria reflect evolving concepts and, in the case of Asperger syndrome, alternatives have been set out, notably by Gillberg (1998).

For many, diagnosis remains the crucial first step in planning the care of someone with an autistic-spectrum disorder. It should be part of a broad, multidisciplinary assessment that takes account of:

- the level of cognitive ability; identifying discrepancies between verbal and performance abilities as well as the variety of specific disabilities that can accompany any neurodevelopmental disorder
- functional ability; acknowledging the extent to which less obvious problems can increase the degree of handicap. These can be in a wide variety of areas that include social relationships, communication (receptive and expressive), imagination and occupational executive function. Their effect can be to reduce the ability of an individual to look after themselves and to function independently, to take up employment or leisure activities, and to cope with other people
- other, comorbid developmental disabilities, notably attention-deficit disorder, tics, sensory anomalies and dyspraxia as well as epilepsy
- mental capacity; the criteria and their underlying broad principles are well established and the, sometimes subtle, characteristics of someone with autistic-spectrum disorders need to be reviewed against these. For example, difficulty with appreciating social rules and relationships, the outcome of actions, and a too rigid perception of how the world should work might all combine to interfere with an individual's ability to understand a situation sufficiently to come to a valid decision
- other elements such as the risk of coming to harm or of offending.

The aim of this wider assessment is to provide a detailed plan that will assist the patient, with the help of their carers and professionals, to lead as full and as normal a life as possible. However, for the immediate future, the extent to which this can happen will be limited by resources.

Clinical diagnosis, as in the rest of medicine, depends on the combination of history with observed behaviour in different settings. Much will depend on age, context and opportunity. Childhood readily provides opportunities for direct and continuous observation in a variety of social

settings (for example, at school or college). In adulthood, where such opportunities are less, there is a greater emphasis on office interviews. Many individuals with autistic-spectrum disorders misperceive their circumstances so that a comprehensive picture will need to draw on the accounts of others such as a friend, carer, teacher, sympathetic employer or supervisor. A developmental history is always desirable and essential in less straightforward presentations if diagnostic doubt is to be avoided. However, this may be unobtainable in the absence of surviving parents or older family members, and even when they are available, the account may be coloured by the desire for the diagnosis together with a greater public knowledge of the symptomatology of autistic-spectrum disorders. School records may be of help but are often disappointingly irrelevant, contradictory or have been destroyed. Individual symptoms are not pathognomonic of autistic-spectrum disorders; other disorders may give rise to impairments in social understanding or non-verbal communication. Indistinct diagnostic boundaries and overlapping concepts bring the risk of an over-inclusive diagnosis that medicalises too broad a range of interpersonal and social difficulties. In the end, much will depend on the extent of the experience of the diagnostician, and the scrupulousness in applying standard criteria as well as the ability to recognise alternative diagnoses.

The diagnostic process must take account of the individual's culture and ability to communicate. Where the clinician is unfamiliar with the individual's culture, it is essential to enlist a variety of resources to help the family to engage in the diagnostic process as well as to inform the clinician. This applies particularly to those who come from an ethnic group unfamiliar to the service as well as those with other disabilities, hearing or visual impairment or a degree of general learning disability. Allowance must be made for the way different cultures might affect how families interpret the symptoms, potentially placing a different emphasis on social impairment as compared to communicative difficulties (Dyches *et al*, 2004; Mandell & Novak, 2005). There is also the potential for clinicians to misinterpret or miss symptoms when they present in someone from another culture or where a different language is spoken.

Asperger syndrome is identified by a variety of criteria. It is on a spectrum of severity, therefore, that a further judgement has to be made (as for any psychiatric disorder) as to whether the dysfunction is causing sufficient distress or difficulty, whether to the individual or to those around them, to qualify for the diagnosis.

Autistic-spectrum disorders may complicate psychiatric disorders across all the areas of psychiatry, the treatment of these comorbid conditions giving psychiatry its major role. These mental health problems may range from adjustment to the presence of autistic-spectrum disorders, whether by the individual or by those around them, through to the more specific disorders, notably attention-deficit hyperactivity disorder (ADHD), mood disorders, obsessive-compulsive disorder and, in some cases, psychosis. It may not be at all clear at what point a symptom of autistic-spectrum disorder is sufficiently pronounced for it to become the basis of a psychiatric disorder in its own right (Berney, 2004). While it is doubtful whether autistic-spectrum disorders predispose to schizophrenia (Tantam, 2003; Howlin *et al*, 2004), they certainly do not protect. However, the phenomenological overlap with schizophrenia spectrum disorders can make it difficult to disentangle one from the other. DSM-IV (American Psychiatric Association, 2000) resolves this by a hierarchical approach, making pervasive developmental

disorders an exclusion criterion in the diagnosis of schizophrenia and ICD-10 excludes 'simple schizophrenia' from the diagnosis of Asperger syndrome). The potential for confusion means that clinicians require:

- reasonable familiarity with autistic-spectrum disorders in their various manifestations
- experience of a wide range of psychiatric disorders
- a developmental perspective; this is not easy, as by adulthood it becomes increasingly difficult to get the childhood history that might clarify the diagnosis.

Diagnostic instruments help the clinician to collect the right information systematically for matching against agreed criteria. Although the criteria are evolving, they do hold clinicians to a consistent threshold at that time and the construct may be refined by an algorithm. The variety of instruments, ranging from screening questionnaires to interview frameworks to structured interview schedules, indicates the difficulties in agreeing the concept, establishing a diagnostic threshold and in maintaining consistency. The development of diagnostic tools, both for history-taking and for clinical examination, has encouraged a move towards a dimensional view of the symptomatology. While the emerging algorithms serve to operationalise diagnostic categories and give a better picture of the spectrum, their mechanical simplicity may be misleading when applied to clinical cases, particularly where there is an overlay of comorbid disorder. Much of the work has been based on childhood observations and only now is it being replicated with adults.

While a number of instruments have been developed to identify autism, few have been designed specifically for Asperger syndrome and, of these, most are screening questionnaires. They vary in the extent to which they are structured, ranging from the very specific self-rating Australian questionnaire (Attwood, 1999) through to the Asperger Syndrome Diagnostic Interview (ASDI), a simple interview framework that is reported as having good interrater reliability (Gillberg *et al*, 2001). The validity and reliability of these and other instruments have yet to be established.

The more formal, structured interviews, such as the Autism Diagnostic Interview (ADI), were initially developed around children with autism, but broader instruments have evolved such as the Diagnostic Schedule for Social and Communication Disorders (DISCO). The Autism Diagnostic Observation Schedule (ADOS), a subject interview designed to elicit the signs of autistic-spectrum disorders, has a module for adolescents and adults who are able and fluent. The International Molecular Genetic Study of Autism Consortium (IMGSAC) (at the time of writing) intends to publish the Family History Interview (FHI), a set of schedules designed to explore the broader phenotype. This will include matched subject and informant interviews as well as an assessment of observed behaviour.

Whatever instrument is used, it is important to take account of childhood as well as current symptomatology wherever possible. The variety of instruments available underscores the range of opinions among specialists about the relative merits of observation of present behaviour versus information about early development (gathered from collateral informants and contemporaneous records). It must be acknowledged that such differences of opinion are an inevitable consequence of the differences in ability and morbidity seen by investigators working in different settings with different patterns of referral.

THE PURPOSE OF DIAGNOSIS

Diagnosis on its own is of limited value. However, it is a starting point for the individual and those around them to see themselves and their difficulties in a new light, making the latter more understandable and the need for support much clearer. The beginning of a more realistic assessment of coping skills and needs, the diagnosis can inform care planning, lead to more appropriate accommodation, education, and occupation and, overall, to more successful integration into the community. It is the gateway to a great deal of information, specialist groups and resources, including financial benefits. A diagnosis can avert a crisis and may allow diversion from the criminal justice system or from hospital admission.

In short, diagnosis has many functions and it is essential therefore that everyone involved appreciates the part it plays for a particular person at a particular time. This will colour the interview and the clinician's cut-off point, depending on whether the diagnosis is:

- for research; where a case may be excluded if there is limited information or simply doubt
- clinical; where the diagnosis is the basis for treatment
- administrative; the diagnosis giving access to services or resources or as part of a legal assessment.

It is often not appreciated that, as there is no definitive laboratory test for autistic-spectrum disorders, the diagnosis is part of a clinical formulation, a judgement that can evolve over time as more information is gathered and circumstances change. In the end, it is a decision that needs to be categorical for individuals who do not find a 'fudge' (such as 'autistic traits') helpful.

Whatever form diagnosis might take, early recognition is important to prevent the secondary disabilities that arise from the struggle to cope with undiagnosed (or misdiagnosed) disability. By adulthood, psychiatry's concern will be predominantly with individuals who have comorbid disorders in addition to their autistic-spectrum disorders. Although identification of autistic-spectrum disorders will give an explanation for an unusual perspective or presentation, it does not automatically mean a change of treatment or management.

Although a diagnostic process, focusing only on the current symptomatology, may be relatively brief, particularly if it complements a psychiatric interview, it can have far-reaching consequences. A more definitive interview, sufficient to refute as well as confirm the diagnosis, can take several hours and therefore is not something to undertake lightly and without sufficient resources.

There is no established route or formal structure by which people come to diagnosis after childhood. Some individuals will have diagnosed themselves from books, self-rating scales or the internet and are seeking formal confirmation. They (or their family/carers) may know a great deal about autistic-spectrum disorders and have made plans for what will happen once the diagnosis is made. Some may be parents who have come to recognise similar traits in themselves after their child has been diagnosed with the disorder. Others may have received a diagnosis in childhood but the diagnosis, or its significance, was lost as they moved between services.

It is essential that there is consent to the diagnostic process, particularly where there is a lack of social understanding or independence.

The wishes of the person with autistic-spectrum disorder can be overlooked by their family and/or carers, who may not recognise that there is the capacity to withhold consent either to the diagnosis or to sharing the information (Royal College of Psychiatrists, 2000).

RECOMMENDATIONS

- 2 Diagnosis should be only one part of a multidisciplinary assessment that might include cognitive, educational, occupational, social and communicative abilities as well as any other systems (for example, motor or sensory) that are relevant to its purpose. It needs to take account of the language and cultural background of the individual and their family.
- 3 The conclusions from such a clinical assessment should be fed back as written reports and minutes to avert the misunderstandings that arise from oral communication. Diagnosis should only be undertaken in the context of counselling concerning the implications of the diagnosis and how the information should be shared.
- 4 Transition planning should recognise that not all young people with an autistic-spectrum disorder will need to make use of adult services, but for those who do, there should be a smooth link between services that passes on information about why and how the disorder was diagnosed together with its implications. Many agencies routinely destroy information about young people after a set period and arrangements should be made to ensure that this crucial information is not lost; a copy might be given to the individual with the disorder or their carer. It should be recognised that those who are moving out of psychiatric services will still require additional support whether they are moving on to education or employment and this should also be the focus of multi-agency planning.

WHO DIAGNOSES?

Who will diagnose the disorder depends on the purpose of the diagnosis. In practice, it is being carried out already by a broad range of professionals, including, for example, psychiatrists, psychologists (educational as well as clinical), paediatricians, speech and language therapists, occupational therapists, nursing staff and researchers. The main stipulations might be, first, that they are familiar with autistic-spectrum disorders and, second, that they are part of a professional group that helps them to maintain a reasonably constant threshold. The risk for many is that, in lacking experience of other forms of psychopathology, they may be over-inclusive.

Psychiatrists should be able to diagnose autistic-spectrum disorders in clear-cut cases. In a clinical team, diagnostic interviews may be allocated to those who are particularly experienced in their administration. The psychiatrist's special expertise is in their ability to distinguish other forms of pathology and their involvement becomes essential where there is comorbid psychiatric disorder or where clinical management is contemplated; the more complex the case, the more necessary becomes a multidisciplinary approach.

VIGNETTE A

A couple, in their early 60s, had been comfortably married for 30 years but recently had been thrown together when their children left home and the husband had retired from a busy academic post to work from home. They came to marital counselling because his wife thought that he had become remote, with little concern for her or her interests. In counselling it became clear that there had been no innate change but rather that their discomfort arose from their changed circumstances and expectations. The counsellor was struck by the husband's unusual detachment and the diagnosis of Asperger syndrome was confirmed by a clinical psychologist. This reassured the wife sufficiently for the couple to negotiate a more comfortable relationship.

Comment: The diagnosis (non-psychiatric) helped the couple achieve a better marital relationship.

VIGNETTE B

A young man with bipolar disorder had had several admissions to an adolescent unit. His rather unusual premorbid personality had been ascribed to his disorder but his odd interests led to a more careful developmental history that brought out his long standing social ineptness and isolation, together with an early language delay. Autistic-spectrum disorder was diagnosed and a more detailed assessment showed that, besides a number of other deficits, he had a disproportionate difficulty in understanding speech. He was not thought able enough to go on to higher education but attended a specialist further education college for students with autistic-spectrum disorders. Over the next 3 years, with substantial support and tuition (with an emphasis on written rather than spoken input) he learned to cope with people sufficiently to do well in exams and move on to university. There he found himself with academic but no social support and he left after twice failing to pass his first year.

Comment: Diagnosis, delayed by the presence of a psychotic disorder, allowed a degree of rehabilitation that would not have been possible from the adolescent unit. Unfortunately, it was not sufficient to allow him to cope with an university place that did not provide the necessary level of support (Berney, 2004).

RECOMMENDATIONS

- 5 Commissioners should ensure that there is access to local, basic diagnostic expertise that would allow for the firm diagnosis of autistic-spectrum disorders in clear-cut cases. They should also ensure access to a second level of diagnostic expertise for those individuals where there is diagnostic uncertainty.
- 6 Services should be well integrated so that clinical diagnosis is not isolated from treatment and that this, in turn, is closely linked to the (non-psychiatric) services that are provided by other agencies.
- 7 Psychiatric training should include experience in the diagnosis, assessment and management of individuals with autistic-spectrum disorders. In particular, there should be some supervised experience with adolescents and adults of normal cognitive ability who have these disorders.

Management

Any management plan begins with a clinical diagnosis and, although it is important that it is not seen to have a monopoly, psychiatric input becomes essential where autistic-spectrum disorders are complicated by comorbid disorders or an alternative disorder has to be excluded.

The mainstay of management lies in the range of non-clinical resources that, besides family input and peer support (from a growing number of self-advocacy groups), include educational (ranging across school, college and university), occupational and social services. Specialist support in various forms, including help with accommodation, education and occupation, is being recommended increasingly; an example is the North Carolina programme for the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) that has extended into adulthood (Schopler, 1997). There are a growing number of treatment programmes aimed at the autistic-spectrum disorders themselves, some at great financial cost to individuals and their families and to services, although the evidence for their effectiveness is very limited. Nevertheless, many depend on their help to get basic entitlements (Powell, 2002).

PSYCHIATRIC MANAGEMENT

There is no evidence of any effective treatment for the core impairments of autistic-spectrum disorders; however, the symptoms will be improved by anything that reduces the individual's anxiety or increases their comfort and sense of well-being. This might be by improved communication, a change to the environment, the relief of physical malaise or the treatment of comorbid psychiatric disorder. The last requires an understanding of the underlying impairment of autistic-spectrum disorders as well as a coordinated approach that includes other agencies and resources.

MENTAL CAPACITY AND CONSENT

The disabilities associated with autistic-spectrum disorders may complicate the assessment of mental capacity and thereby the validity of an individual's consent to treatment. For example:

- difficulties with comprehension (one symptom is a tendency to interpret language literally) which may be masked by superficially good speech
- difficulties with attention and concentration (which may be rooted in severe anxiety as well as being innate) can make it difficult for the person to follow explanations

- problems in coping with change result in an extreme aversion to anything new so that the person refuses to consider any proposal
- a rigid perception of how the world works (or should work), as well as of cause and effect, that may not reflect reality.

LEGAL ASPECTS OF PSYCHIATRY

Most individuals with autistic-spectrum disorders are keen to avoid trouble with the law and most do not offend. This law-abiding respect for rules can be offset by a number of predispositional factors that make the individual more vulnerable. Examples of these are:

- social naivety and misinterpretation of relationships, which leave individuals open to being drawn into illicit relationships, to intimidation, or to exploitation as a stooge. Limited emotional knowledge hinders understanding of adult situations and relationships and can, for example, lead to social attraction or friendship being mistaken for love
- an unusual passivity that leaves the individual open to being influenced and exploited by others (for an example see vignette C)
- misinterpreting rules, particularly social ones, whereby individuals can find themselves unwittingly embroiled in offences such as 'date rape'. Television and video scenarios may be copied without understanding that they may not be intended for translation into real life
- difficulty in reading social signals and cues. For example, a difficulty in judging the age of others can lead the person into illegal relationships such as sexual advances to somebody under age, particularly likely where social ineptness has made it more comfortable to associate with a younger peer group
- impulsivity, sometimes violent, that may be a component of a comorbid attention-deficit disorder, a state of anxiety turning into panic or a confusing blend of both. The result is a response that is out of proportion to the situation (for example, a tantrum) that others then misinterpret as threatening

VIGNETTE C

An adult male (25 years old) had been involved in credit card fraud by a friend who was one of a group that constantly took advantage of C to the extent of stealing from him. It was long standing: at 13 years, a 'school friend' talked him onto a house roof and pushed him off. C told the psychiatrist that he was unable to 'say no to people.' He did not appear unusual at interview, smiling frequently and using eye gaze appropriately, and he denied that there was anything wrong with him. Although the psychiatrist decided initially that he did not have autistic-spectrum disorders, a subsequent developmental history, taken from his parents, revealed that he had been floridly symptomatic in early childhood.

Comment: an unexplained, unusual trait led to a developmental history that, in this case, was the key to understanding the needs of this person and his future management.

- an innate lack of awareness of the outcome, which leads the individual to embark on actions with unforeseen consequences. For example, what starts as minor violence may end in death, or as fire-setting may result in a building's destruction
- an innate lack of concern for the outcome, which can result, for example, in an assault that is disproportionately intense and damaging. Not infrequently there is a lack of insight and a denial of responsibility, blame being ascribed to someone else, that has its roots in an inability to see their inappropriate behaviour as others see it
- overriding preoccupations, which can lead to offences such as stalking, or compulsive theft. Here admonition can increase anxiety and consequently a ruminative thinking of the unthinkable that increases the likelihood of action
- in formal interviews, misjudging relationships and consequences, which can permit an incautious frankness. Private fantasies may be no more lurid than those of many in the normal population but may be startling in their clinical detachment, their obsessionality and in their disclosure
- lacking motivation to change, individuals can stay stuck in a risky pattern of behaviour – a problem that may be made worse by comorbid dysphoria, anxiety or any other mental state that reduces flexible thinking.

Many of these factors, affecting the capacity to make valid decisions, will limit the individual's level of responsibility. It may be argued that the degree of deficit in understanding the perspective and autonomy of others is such as to leave the individual unable to understand or appreciate the impact their behaviour has on others (Barry-Walsh & Mullen, 2004).

The frequency of different types of offence is unknown. There is an element of chance as to whether the person becomes identified as an offender that depends on such factors as the recognition of the autistic-spectrum disorder and the attitudes, support, supervision and tolerance of those around. A variety of reasons can lead individuals with these disorders to become entangled either with the criminal justice system or with the civil courts.

Autistic-spectrum disorders can (but do not necessarily) affect the ability of someone to give an accurate account of an event (i.e. to be a reliable witness) because of such factors as:

- an unusual perception of the significance of events, whether as observer or performer, that increases the risk of misinterpretation of what they have seen or heard
- difficulty with the dimension of time. Although the sequence of events may be correctly recalled, the perception of the relative periods of intervening time may blur the distinction between something that happened the previous day, week or year
- difficulty in distinguishing their own actions from those of others. This may extend to the confusion of reality with observed fiction
- difficulty with the normal structure of official interviews, whether in the police station or the witness box; the unfamiliar surroundings and circumstances will increase any innate disability in communication, both verbal and non-verbal. The person with an autistic-spectrum disorder can have difficulty with understanding the interviewer,

particularly if questions are complex, indirect or use metaphors or colloquialisms. Their responses, with inappropriate or absent vocal tone or facial expression (particularly anxious smiling) can mislead the interviewer. Delays in processing speech or selective mutism are easily misinterpreted as wilful

- the interview can be distorted by the misinterpretation of rules and relationships, with undue compliance complicated by a rigid tendency to adhere to (and believe in) a story once it is in the individual's head.

There is the risk that the person may not be recognised as a vulnerable adult, particularly where he has a good, academic awareness of right from wrong and the nature of the court. The criteria for fitness to plead established in *R. v. Pritchard* (1836) emphasise the cognitive abilities of the defendant which may well be limited where the legal issues start to become complex (Barry-Walsh & Mullen, 2004) and further compromised by a limited ability to present him- or herself, a disability that has been highlighted (in England and Wales) by the removal of the right to silence (Gray *et al*, 2001).

It does not follow that these difficulties are invariably present in all cases of autistic-spectrum disorders, simply that, where relevant, they should be sought out as part of the assessment. Once recognised, many of them can be minimised by adjusting interviewing styles to allow for linguistic limitations, using visual materials such as text and diagrams to support speech, allowing sufficient time for the person to understand what is happening and to express themselves, and checking that a point has been understood before moving on. Preparatory visits to court may help to familiarise the individual with the setting and the proceedings, which might then be made more manageable by arranging for appearances to be at times that are predictable and of a set and limited duration.

Some individuals with autistic-spectrum disorders are not distressed by the structure of prison life and may even be reluctant to return to a less predictable life in the community. However, many are vulnerable people who find themselves in conflict with the structure and at risk of serious harm from others (Scottish Executive, 2004); at the least they are particularly liable to bullying and other forms of victimisation. For some the degree of stress and consequent arousal may be sufficient to produce a psychotic state.

RECOMMENDATION

- 8 For those individuals with autistic-spectrum disorders who become involved in legal processes, there should be routine access to psychiatric services that can:
 - (a) distinguish autistic-spectrum disorders from other psychiatric disorders and, in particular, from the personality disorders as well as other neuropsychiatric disorders and learning disability
 - (b) recognise the potential impact of these disorders on responsibility, mental capacity, fitness to plead and the ability to bear witness
 - (c) encourage awareness of, and provision for, autistic-spectrum disorders in court processes and in subsequent care
 - (d) develop appropriate interventions and therapies within secure and forensic settings.

PHARMACOTHERAPY

There is little research-based evidence for the use of medication with autistic-spectrum disorders in adolescence or adulthood, although there is considerable material on its use in individuals with a learning disability, many of whom will also have autistic-spectrum disorders. This research recognises the real risk of its overuse. Neuroleptics, particularly haloperidol, have been shown to be effective for a variety of the symptoms of autistic-spectrum disorders but their utility is offset by their adverse effects. There are promising reports from trials with the newer neuroleptics, used in low doses (McDougle *et al*, 1998), and with the selective serotonin reuptake inhibitors (SSRIs) (Moore *et al*, 2004), both to reduce arousal and to improve mood. Data on the effects, both short and long term, is limited, but clinical experience indicates that individuals with autistic-spectrum disorders can show an idiosyncratic response to medication. The difficulties in evaluating the efficacy of a drug and, in particular, the substantial strength of the placebo effect, have been highlighted by studies investigating the response to secretin infusions in younger individuals with autism (Sandler *et al*, 1999; Sandler & Bodfish, 2000).

Medication is useful in the management of certain comorbid disorders (such as epilepsy, attention-deficit disorder, anxiety, obsessive-compulsive disorder and depression) and as part of a coordinated approach to behavioural disturbance (Santosh & Baird, 1999; Volkmar, 2001). However, it is only one component of an approach that includes other modalities such as psychological therapies, education and environmental change. The aim of such a multimodal approach to intervention is to help the individual engage in interactions and education, and so develop a more socially adaptive relationship with the world around them. There is the aspiration, sometimes realised, that the change will be sufficient for medication then to be relinquished.

At times of stress some individuals with autistic-spectrum disorders may develop symptoms that are difficult to distinguish from those of psychosis. Early treatment of the latter is so important to the prognosis that it should not be delayed by diagnostic doubts. At the same time it must be recognised that, once someone has been established on neuroleptics, it can be difficult to disentangle the two disorders.

The association of epilepsy with autism (Tuchman & Rapin, 2002) has led to trials of various forms of anti-epileptic treatment, although in the absence of clear evidence of seizures, the results are equivocal (Belsito *et al*, 2001). The arguments expressed clearly in the debate on the use of surgery (Palac *et al*, 2002) also apply to the use of anti-epileptic drugs. The issue is confused by the effectiveness of these drugs in the treatment of psychiatric symptoms such as unusual irritability or bipolar disorder.

PSYCHOTHERAPIES

A variety of psychological therapies have been advocated that range from the psychoanalytic to the behavioural, although there is only limited knowledge of how autistic-spectrum disorders affect either their deployment or their outcome. The indiscriminate use of psychodynamic approaches left a reactionary aversion, reinforced by the difficulties in communication and symbolization that go with these disorders. Traditionally, assessment for

exploratory and cognitive therapies focuses upon the individual's capacity for verbalisation, symbolisation and ability to access thoughts and emotions. It also considers their capacity to establish a relationship with a therapist that is characterised by a mutual consideration of the patient's experiences. These are all skills in the very areas that are limited in autistic-spectrum disorders.

In learning disability, systematic reviews have supported the use of behavioural and cognitive behavioural interventions. Other approaches include creative therapies, psychodynamic therapies, counselling and integrative psychotherapies as well as systemic work (whether individually or in groups). These are much valued and widely used but the evidence for their effectiveness is limited to single or multiple case reports. Although none claim to cure the core deficits of autism, they can enhance communication and problem-solving, complementing educational approaches that, for example, teach skills such as 'theory of mind'. The focus is on the management of interpersonal difficulties as well as of the system around the individual.

The choice of approach, directed at the individual (whether on their own or as part of a group) will be influenced by the level of ability as well as by the nature of the disorders that require treatment; this covers a broad range that includes:

- individuals, often with a more pronounced learning disability, who present with challenging behaviour, pervasive ritualistic behaviour and communicative difficulties. Historically, behavioural programmes and environmental manipulation have been effective.
- individuals who are more able and present with symptoms of autism such as obsessive-compulsive difficulties and problems with social adjustment and relationships. Behavioural, personal construct and cognitive behavioural therapies have been particularly effective but should be carried out by a skilled practitioner who can adjust the intervention to the characteristics of autistic-spectrum disorders.
- individuals who present with psychiatric disorders that are comorbid with autistic-spectrum disorders. While requiring the appropriate psychotherapeutic treatment, the exact approach will depend on the expertise available and whether they require an immediate solution-based technique or one that addresses longer-term issues.

However, like other groups who are difficult to engage in more dynamic therapy because of their difficulties with cognition or communication, individuals with autistic-spectrum disorders are likely to be under-represented in psychotherapy services (Royal College of Psychiatrists, 2004). Such initiatives as exist within adult psychotherapy services are in relative isolation rather than as a part of the mainstream. They tend to encompass a wide range of therapies, incorporating elements of a number of theoretical approaches and are delivered with varying degrees of intensity. These range from the basic psychoeducational component that should be integral to all mental health work, through various forms of psychological therapies, to formal psychotherapy (Department of Health, 1996).

Families and carers may be the chief source of intervention and advocacy for the person with autistic-spectrum disorders. However, besides practical help with their caring roles, they have to come to understand the disability and adjust to the diagnosis, often only after years of uncertainty and self-blame. Here a psychodynamic consultation or formal systemic

therapy may be helpful. Particularly important is family intervention that reduces the level of emotional stress.

Counselling services have developed for individuals with Asperger syndrome within the private/voluntary sector. For example, Relate has trained staff in many of its branches to deal with the special problems of couples, where one or both of them have an autistic-spectrum disorder, and usually use a person-centred approach. Growing interest in seeking counselling reflects the desire of individuals with autistic-spectrum disorders or their carers to have help in overcoming the problems of having the disorder, although recognising the autistic-spectrum disorder itself is not susceptible to psychological intervention. Requests for intervention are often based on the following specific problem areas:

- coming to terms with the diagnosis
- relationship problems, sometimes with friends but more often with partners
- cognitive problems associated with the disorder, particularly those that have most impact on the quality of life with others, for example, lack of empathy or dysexecutive disorder.

Whatever the treatment, it is essential that the therapist has an understanding of the possible characteristics, both strengths and difficulties, that may accompany autistic-spectrum disorders. Visual strategies have provided effective adaptations to verbal communication and the creative therapies have developed to enhance communication.

Services

Most individuals with autistic-spectrum disorders will require local support from a wide variety of agencies and disciplines; this should involve families and carers and be adapted to different cultures and beliefs. It needs a broad-based strategy, going beyond health, education and social services to include, for example, occupational, legal, recreational and voluntary services. These services need to take account of families from ethnic minorities who may have linguistic barriers, mistrust, fear, misunderstanding as well as a different understanding of the need for treatment. All these affect their access to the organisation, interaction with it and choice of treatments (Mir *et al*, 2001; Dyches *et al*, 2004). Psychiatric services are only one component of this wider system and are likely to be required by a minority of people with autistic-spectrum disorders.

The development of such psychiatric services will vary with the different administrations across Britain. It is essential that they are not set up solely to provide assessment or diagnosis, but are linked to the provision of treatment and other services. Taking into account the varied ages and circumstances of individuals with autistic-spectrum disorders, it is a broad remit that will involve all the psychiatric specialties and draws on the non-psychiatric specialist services and their expertise.

Although psychiatrists need to be familiar with autistic-spectrum disorders, the level of expertise will vary, ranging from sufficient knowledge and experience to recognise these disorders, through to the autism specialist whose main role might be to support other psychiatrists. Whatever the local provision, there will be occasions requiring a greater degree of specialist expertise, for example, in more complex cases whose diagnoses are less clear-cut, who have not responded to standard treatments or who require unusual services. There should be the facility to draw on individuals, teams and admission facilities with particular expertise – tertiary services that are available at a regional level.

PSYCHIATRIC SERVICES IN THE COMMUNITY

The growing number of specialist services for the social care and education of individuals with autistic-spectrum disorders give a foundation on which psychiatric services can develop. These services, many in the independent sector, are a rich source of knowledge on the effects of autistic-spectrum disorders and the resultant needs, both in general and for those individuals for whom they have direct responsibility. The high prevalence of comorbid disorders means that there will be a need for psychiatric input (for both the service and the individual) together with a framework that ensures their close

coordination. However, this means that a service can find itself forced with the arrival of a group of individuals in a locality whose degree of disturbance has earned them their funding and export out-of-area. They require specialist support from health services that, in the absence of planning and funding, might become overstretched and unable and/or unwilling to respond. There is no formal machinery either to control such developments by the private sector or to involve the health service in their planning.

Innovative models emerging in the independent sector can be a valuable spearhead for wider general developments but should be coordinated with National Health Service planning rather than replacing it. The development of cost-effective services must involve all parties in planning and commissioning these different components. The National Autistic Society have fostered the development of informal arrangements through a number of collectives, 'Partners in Autism', that offer the basis of local strategic planning across the UK.

Scotland, England and Wales are moving towards a unification of health and social care commissioning that might make it more straightforward to implement such an arrangement; although this is not altogether supported by the experience of Northern Ireland and the Republic of Ireland where such an association has been long established.

PSYCHIATRIC TREATMENT UNITS

Autistic-spectrum disorders themselves do not require psychiatric treatment, let alone warrant admission. It is the association with psychiatric disorders that do need admission that creates the need for autism-friendly treatment facilities. The quantity of residential accommodation is increasing, much of it advertising itself as providing for individuals who have challenging behaviour in addition to their autistic-spectrum disorders, so that there is less demand for hospital admission and a greater readiness to manage disorder in the community.

Admission, whether as day- or in-patient, can be more daunting for individuals with autistic-spectrum disorders than for most. At present, few psychiatric units provide the necessary settings or the staffing levels to prevent conflicts or to protect the person with these disorders from bullying and harassment. It is difficult for staff to understand rituals and food fads and therefore to accommodate them. In addition, not only do psychiatric units lack appropriate psychoeducational programmes, many use group approaches that are ill-suited to autistic-spectrum disorders and may cause individuals to refuse therapy for reasons that they are unable to articulate.

All this puts a greater emphasis on avoiding admission, but when it becomes necessary, it should be to an area adapted to autism. This means an environment attuned to the constitutional needs as well as to the psychiatric disorder. Such an environment (including people, buildings and programmes) should be structured, predictable and one in which stimuli are of low intensity, the overall aim being to reduce arousal. It should be characterised by regular routines, consistent responses, clear (and preferably visual) communication, and people who are present in limited numbers and are reasonably familiar, whether they are staff or patients. Staff need to be consciously aware of the sensitivities and perspectives of the person with autistic-spectrum disorder rather than relying on their intuitive responses: this means that autistic-spectrum disorders need to be part of their training

and it also requires good liaison with carers and services that specialise in working with this disorder.

For some this will be insufficient; their degree of autistic-spectrum disorder, with the associated perceptual sensitivity, emotional fragility and need for predictability, is such that they require an unusual degree of structure with a specialist environment that uses programmes such as TEACCH (Schopler, 1997) and specialist staffing. In addition to a sympathetic environment, these units provide therapeutic and educational programmes designed to minimise the disabilities that arise from autism as well as specific treatments for comorbid psychiatric disorders. There are very few such specialist hospital places in the UK that provide for limited periods of assessment and treatment (as opposed to longer-term, specialist social care). Although an increasing number of hospitals declare their interest and availability for individuals with autistic-spectrum disorders, few are dedicated to this group, who can find themselves on units where the ethos, training and experience is more appropriate to individuals with a generalised learning disability. Specialist adolescent places are even scarcer and it is firm governmental policy that they should not be admitted to adult units. Most adolescents who require an out-of-home placement are managed within specialist schools. When these are unable to cope with their degree of disturbance they are especially likely to find themselves accommodated in ad hoc isolation in the community or, sometimes, are returned home to parental care.

A few individuals will be sufficiently violent or dangerous to warrant an extended hospital stay. However, for many it is not unusual for their short-term admission to become extended as there is a realisation that, even after a lengthy period of hospital admission, they are going to require a specialist community placement with substantial resources. This gives admission a flypaper quality, trapping the patient in hospital. Consequently, for some, there has been the rapid development of a package of care around the person in their existing community. Unfortunately, this often results in an isolated house that brings its own difficulties in providing proper managerial supervision of, and clinical support for, the staff.

The legality of care in such a placement is a further issue. Where the behaviour is sufficiently violent to require frequent restraint, seclusion or involuntary medication, its imposition requires the authority of a Mental Health Act and consequently hospitalisation. In Scotland, the Adults with Incapacity (Scotland) Act 2000 enables treatment in the community of those adults who fall within its remit, but it remains to be seen whether the Mental Capacity Act or a new Mental Health Act will permit this in England and Wales.

The difficulty of planning and developing new resources has meant that the reduction of National Health Service hospital beds has led to a compensatory growth of private sector resources for this group of individuals that require extended hospital placement.

PSYCHIATRIC SPECIALTIES

SERVICES FOR ADOLESCENTS

While autism is becoming more readily recognised and managed from early childhood, 'milder' forms in someone of normal ability might only be highlighted by the developmental changes of adolescence, the difficulties of

peer relationships or the more complex structure of secondary schooling. New philosophies, emphasising inclusion, the development of the extended school and community psychiatry, might make it easier for individuals to obtain the necessary support and adaptation. Psychiatry may become involved because of problems in adjustment, including a lack of social awareness leading to social isolation and victimisation, sexually or socially inappropriate behaviour or because of the development of comorbid disorder including self-harming or parasuicide. It is in the core competencies of the psychiatrist to identify autistic-spectrum disorders and it is essential that the diagnosis is passed on as the young person moves on to other services, through copies of reports held by the person or their carers, by the involvement of the personal advisor from Connexions (in England and Wales) within a multi-agency framework, and, at the least, by ensuring that the general practitioner is kept informed. It is important to recognise that there may be relatively few services for older adolescents as they move out of the child and adolescent mental health services.

SERVICES FOR INDIVIDUALS WITH A LEARNING DISABILITY

Increasingly, services for individuals with a learning disability have become familiar with autistic-spectrum disorders, and where there is a significant intellectual disability, they are ready to engage with these individuals. When disturbed, their management is often a matter of improving communication, their environment and their level of support rather than of more traditional individual psychiatric treatment. These issues, while familiar to learning disability psychiatry, also apply to individuals of normal cognitive ability, although their ability may well bar their acceptance by an element of the learning disability service, preventing a multidisciplinary assessment, let alone entry, into the coordinated network of care. There is therefore the risk that such vulnerable patients fall between contracts despite their statutory entitlement to psychiatric services (many fall within the provision of the Adults with Incapacity Act (Scotland) 2000 or, in England and Wales, the exhortations of *Valuing People. A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001a,b))

SERVICES FOR ADULTS WITH MENTAL ILLNESS

Services for adults with mental illness are now usually delivered by multidisciplinary community mental health teams liaising with primary care, with specialist developments focused on service-level interventions (early onset psychosis; home treatment and assertive outreach teams) (Department of Health, 1999). Such specialist services usually include the assessment and management of affective disorders and psychosis in the community, the focus of intervention being pharmacotherapy, cognitive-behavioural therapy, family work and psychoeducation. In many areas these services are overstretched and the provision of services for adults with severe mental illness is patchy. Seen as a 'catch-all', they cannot meet the demands that may come with the recognition of developmental disorders, such as autistic-spectrum disorders in adulthood, particularly as it brings with it the need for long-term continuity. Nevertheless (as in Leicestershire and Avon), some local authorities have decided formally that the social workers in the child and adolescent mental health services should take responsibility for the community care assessments for such adults.

Rather than expecting all services to have a high degree of expertise in the assessment of individuals with autistic-spectrum disorders, it may be useful to focus attention on those teams within mental health services for adults where specific diagnostic or management skills are likely to be needed. Examples are the early intervention service, with its emphasis on the differential diagnosis of acute psychosis, and the acute crisis team with its skills in maintaining and supporting vulnerable individuals in the community.

For young people there is an overlap between child and adolescent psychiatry and learning disability psychiatry. However, there are frequently gaps in services between these and the other specialties. As resources become available, it seems likely that adolescent services will take on responsibility for young people up to their 18th birthday. For adults, services might be provided by a combination of psychiatric training, at all grades including consultant, as well as by better liaison with learning disability psychiatry, perhaps buttressed by members of the clinical team (not necessarily psychiatrists) with a special interest and/or expertise in autistic-spectrum disorders.

In practice, services are likely to be shaped by the interests and enthusiasm of those providing the service locally (including the independent sector) as much as by local need. Any change is inhibited by the lack of resources, recruits and the contractual boundaries of the community and hospital teams. The provision of services for individuals with autistic-spectrum disorders will require scope for considerable local flexibility as well as contractual clarity on the part of service commissioners and providers.

RECOMMENDATIONS

- 9 Commissioners should ensure that individuals who are thought to have autistic-spectrum disorders have access to expertise across a broad range of therapeutic approaches, including those relevant to the psychological management of these specific disorders, delivered through autism-friendly treatment facilities that include the whole range of age and ability and take into account cultural factors.
- 10 Referrals should be made within a formal contractual programme (rather than on an individual basis) to ensure that the provider (rather than any individual clinician) accepts responsibility for the care of the individual with the disorder and there should be regional agreement as to the roles of various individual consultants. It should not be assumed that a service can absorb this patient group without specific planning and investment.
- 11 As services for those of working age are often poorly developed, it would be helpful if an 'autistic-spectrum disorders champion' were identified within each strategic health authority area. This would be a senior clinician with experience of the psychological management of autistic-spectrum disorders, who would have a specific responsibility for advising on treatment options outside of child and adolescent mental health services.

Future research

Initially, there was an emphasis on the biology of autism in plans for research (Medical Research Council, 2001) but the perspective has broadened subsequently (Charman & Clare, 2004). Even so, the following areas, concerning adults and older adolescents, deserve further attention:

- epidemiological information, in particular:
 - the relationship between traits and autistic-spectrum disorders; the threshold at which these disorders should be diagnosed
 - the prevalence and distribution of these disorders in adulthood; for example, their whereabouts in the community and, particularly, in specific ethnic groups and vulnerable groups such as those who are homeless, in prison or in hospital
 - the physical health of individuals with these disorders, their survival and the quality of adult life and old age
- the relationship of comorbid psychiatric disorder to autistic-spectrum disorders; prevalence, nature, natural history and response to treatment, notably depression and anxiety (including dysphoric states); obsessive-compulsive symptomatology; motor disorders and catatonia; borderline conditions and psychoses
- the extent and nature of offending behaviour in this population, its natural history and the effectiveness of treatment programmes
- the ways in which these disorders affect legal responsibility, including the capacity to make decisions and to give evidence
- the impact of these disorders on the families of adults, including their partners and children
- the impact of families on individuals with these disorders. The extent to which the quality of family relationships relates to the individual's level of adjustment in adulthood
- evidence for the effectiveness of interventions, particularly for those which are being adopted by families, for example, the gluten/casein exclusion diet; the use of omega-3 oil and of 5-hydroxytryptophan
- the nature and effectiveness of psychotherapy in these disorders.

RECOMMENDATION

- 12 Research should be encouraged into the impact of autistic-spectrum disorders on adolescence and adulthood as it affects clinical psychiatry.

The training of psychiatrists

Autistic-spectrum disorders span all psychiatric specialties. They have received most attention in child and adolescent psychiatry and learning disability psychiatry where a substantial body of expertise has developed. The following schema for competencies in this area was prepared by a joint working group that included representatives of the specialist advisory committees for training in child and adolescent psychiatry and learning disability psychiatry of the Royal College of Psychiatrists and from the Royal College of Paediatrics and Child Health. Recognising that, outside these specialties, there is little training in the diagnosis and management of autistic-spectrum disorders, the schema is given to provide a basis for discussion as the Royal College of Psychiatrists reviews the overall programme. (The curriculum is regularly reviewed; for the current version visit the College's website at <http://www.rcpsych.ac.uk>).

LEVEL 1. COMPETENCE REQUIRED TO OBTAIN MEMBERSHIP OF THE ROYAL COLLEGE OF PSYCHIATRISTS

KNOWLEDGE

- Demonstrate a working knowledge of the clinical features of autistic-spectrum disorders (Royal College of Psychiatrists, 2001, p. 30).
- Have a basic understanding of the core deficits in these disorders and the implications of these for the adjustment and care of individuals and their families.
- Be able to describe the causes and development of the disorders (Royal College of Psychiatrists, 2001, p. 33).

SKILLS

- Have the ability to relate to a person with autistic-spectrum disorders and their family.
- Be able to take a developmental history (and to recognise the pointers to these disorders).

EXPERIENCE

- Have the opportunity to interview, assess and treat people with autistic-spectrum disorders (learning objectives for senior house officers).

LEVEL 2. COMPETENCE REQUIRED TO GAIN ACCREDITATION AS A SPECIALIST IN PSYCHIATRY

KNOWLEDGE

- Have knowledge of the indications, contraindications and limitations of interventions including the use of medication and the place of investigations.

SKILLS

- Be able to diagnose autistic-spectrum disorders in straightforward cases using standard diagnostic criteria. Also be able to recognise and/or diagnose those conditions that are often comorbid or part of the differential diagnosis (for example, learning disability, attention-deficit disorder, Tourette syndrome, epilepsy, dyspraxia, mental illness).
- Be able to contribute to the development of a multi-agency intervention plan that includes psychological, educational and social contributions.
- Be able to work psychotherapeutically with the family and to help them to understand and come to terms with the individual's disability.
- Have the ability to recommend medication where necessary for comorbid psychiatric conditions.
- Be able to engage and work with local support groups.

EXPERIENCE

- This will be achieved through supervised clinical practice in an appropriate setting with specialist expertise in the diagnosis and management of autism supported by academic study.

LEVEL 3. A CONSULTANT WHO IS SPECIALISING IN AUTISTIC-SPECTRUM DISORDERS PSYCHIATRY

KNOWLEDGE

- (As for Certificate of Completion of Training but in greater depth).

SKILLS

- Have the ability to carry out a very full and comprehensive assessment of an individual with an autistic-spectrum disorder (usually as a member of a multidisciplinary team) including the more borderline and complex presentations. This will include training and/or experience of a standardised approach to taking a developmental history and in observational assessment (for example, Autistic Diagnostic Interview, Autistic Diagnostic Observation Schedule, Diagnostic Interview for Social and Communication Disorders). A similar level of competence is required in the diagnosis of those conditions that are often comorbid or part of the differential diagnosis.

- Be able to liaise with, and to consult other providers of services for individuals with autistic-spectrum disorders.
- Have experience and skills in initiating and leading the use of medication, psychotherapeutic and other interventions in the management of autistic-spectrum disorders as part of a multidisciplinary intervention strategy.
- Show involvement in early intervention programmes, parent support groups and other activities supporting and informing families.
- Have knowledge and ability to advise the courts concerning the nature of a person's condition, its relevance to behaviour and the best ways of treating and/or managing the condition and fostering the person's development.
- Have the ability to play a lead role in the development of services.
- Have the ability to contribute to teaching and research on this topic and in related areas.

EXPERIENCE

- This will be achieved through continuing clinical practice in an appropriate setting with specialist expertise in autism supported by continuing professional development.

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