



Z. JABARIN, J. CROCOMBE, E. GRALTON AND S. CARTER

Service innovations: Maple House – an autistic-friendly NHS facility

Maple House, a unique in-patient facility for learning-disabled adults with autism, has recently been developed in Exeter. The design of this facility has been based on the principles of Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), a well researched and validated educational programme developed for autistic children in North Carolina, USA. The design tenet of Maple House was that the environment should reflect these principles, facilitating communication and, therefore, allowing the comprehensive assessment of autistic individuals. Overall, the service provision for this group in the UK is deficient. Maple House may be a model for future NHS facilities for people with autism.

Background

In the early 1990s there was increasing recognition of the presence of autistic spectrum disorders among adults seeking help from the learning disability and adult psychiatric services in Exeter. The ICD–10 (World Health Organization, 1992) had introduced the diagnosis of atypical autism, incorporating many individuals formerly precluded from a formal diagnosis of autism because of their low level of intellectual function. Around the same time, epidemiological studies showed an incidence of autism (including higher-functioning individuals) as high as 71 per 10 000 (Ehlers & Gillberg, 1993). Some of these individuals had attracted alternative diagnoses of personality disorder, obsessive–compulsive disorder and occasionally schizophrenia. Clinical practice and research into autism has traditionally focused on young children. Autism, however, is a complex, heterogeneous, lifelong condition (Larkin, 1997). The philosophy of normalisation (Wolfensberger, 1972) and the 1971 Government White Paper *Better Services for the Mentally Handicapped* (Department of Health and Social Services, 1971) encouraged community integration as part of community care. It was assumed by many that patients would lose their obsessional and ritualistic behaviours once they left institutional settings. However, the integration of autistic and non-autistic people together into community settings has proved problematic. The author's own experience was that such individuals frequently had to be sent away to independently run secure facilities because local services could not cater for their health needs. A suitable local service to assess, treat and appropriately manage adults with these disorders needed urgent development.

Research

In 1997 the Council of International Hospitals, a professional advisory group in London, was commissioned by the Exeter and District Community Health Services Trust to undertake an international search for appropriate research-based models for in-patient assessment and treatment of adults with autism. Despite an intensive search of literature and liaison with a variety of national and international organisations, no in-patient model allowing the comprehensive assessment and management of adults with autism was identified.

There were, however, a variety of services and specific initiatives for autistic adults scattered around the UK and internationally. These had resulted primarily from the efforts of locally interested professionals and parents rather than any centralised initiative. Services for adults lag a long way behind those for children and no country provides a range of services sufficient to meet the needs of adults with autism (Morgan, 1996).

TEACCH

Of these treatment programmes, Division TEACCH, based in North Carolina, was selected as the most promising model for potential application to an adult NHS in-patient facility. TEACCH was developed in the early 1970s by Eric Schopler and is now a comprehensive and publicly supported state-wide programme with an extensive research base (Schopler, 1997). The TEACCH approach focuses on the development of a programme and environment based on an individual's skills, interests and needs. Individualised assessment, structured teaching and a respect for the 'culture of autism' are key principles (<http://www.unc.edu/depts/teacch/>).

Individuals with autism often have specific strengths for visually processing special interests and related memory skills, which, in a suitably structured environment, can offset many of their deficits. Of special benefit is the use of visual structures involving the physical layout and division of the environment, schedules for when activities occur, visual learning systems and visual organisation of materials. The principles of TEACCH can potentially serve people of all ages and levels of functioning who have received a diagnosis of autism or related handicap (Schopler, 1997).

Characteristics of autism

The biological basis of autism produces cognitive styles and behaviours that are often highly resistant to change. Many cannot be significantly modified by standard



cognitive or behavioural therapies or pharmacological interventions. When new skills cannot be learned or behaviours modified, the environment has to be adapted appropriately (Schopler, 1997). There can also be extreme sensitivity to a variety of environmental stimuli (Grandin, 1995, 1997). Also, there is a wide variety of medical disorders associated with autism; the rate of epilepsy may be up to one-third of adults with autism (Gillberg & Coleman, 1996) and complex partial seizures can produce additional psychological and behavioural disturbance. Adults with autism have often been cared for in a wide variety of environments ranging from those who remain in their families of origin to those who were placed in hospital or institutional care almost from infancy. The complex interaction of these environments with autistic individuals can produce a wide range of problems. Some present with behaviour that is a danger to themselves or to others and may need detention under the Mental Health Act 1983 to allow comprehensive assessment and management. The integration of these patients into mainstream mental health and learning disability facilities is often difficult. All these issues mean that a suitable hospital facility specifically designed for individuals with autism would be a valuable resource.

Design of Maple House

In 1997 two of the authors, Z.J. and S.C., visited Division TEACCH in North Carolina to see the community-based facilities that were available using the TEACCH principles. Professor Gary Mesibov, the current director of Division TEACCH, expressed his support and enthusiasm for the new development. A case was then presented to the local health authority on the potential cost-effectiveness of the project, given that a number of autistic adults were at that time on remote extra-contractual referrals to secure learning disability provision in the independent sector. A planning group was established that included a parent with two children suffering from autism, the former headmistress of a National Autistic Society school, the consultant psychiatrist and psychologist in the learning disability service, three senior nurses with experience in challenging behaviour services and an architect who had a son with autism.

The overriding principle was that the environment itself should communicate as much as possible to the individuals with autism. Rooms should have specific functions, rather than be multi-purpose, so the individuals with autism would have clear expectations about the sort of activities that would take place as soon as they entered into a particular area. The décor was varied to differentiate functional areas. The fabric of the building had to be robust enough to cope with a variety of physical challenges, some less obvious than others (e.g. some autistic people like to disassemble fittings, strip electrical wire or tear fabric). All fittings and furniture were examined and approved for suitability in the new environment. The activity rooms have doors leading to individual gardens that enclose the complex. This allows individuals to remove themselves from distressing

situations to tranquil areas rather than resort to physical violence. All doors open outwards to facilitate exit from rooms. The alarm system provides room-by-room coverage via a vibrating pager system carried by staff. This avoids loud alarms likely to destabilise autistic individuals or unnecessarily divert staff to view a central control panel. This six-bedded facility was built in 28 weeks on the site of a community hospital in Exeter, completed in January 1998 and came in on budget at under £500 000.

Operation

Staff had 2 weeks of in-house training covering cognitive and behavioural aspects of autism, TEACCH (Schopler, 1997), the principles of 'total communication' (Evans, 1982) and 'gentle teaching' (McGee & Menolascino, 1991) and breakaway techniques. Collection of a variety of data, including violent incidents, staff injury and medications, are recorded on a Microsoft Excel spreadsheet, which can reproduce the information in graphical form. Plans for a more powerful database using Microsoft Access are under consideration, but will require additional funding.

The assessment process consists of a full medical history from patient and carers and a review of past psychiatric notes, as well as a variety of standardised assessments including a health screening questionnaire, psychometric assessment, occupational therapy and speech and language assessments in addition to the use of the Childhood Autism Rating Scale (CARS; Schopler et al, 1988) and an adapted challenging behaviour checklist (Harris, 1990). It is envisaged that comprehensive assessment and the implementation of appropriate strategies will take 18–24 months. There is already a waiting list for admission.

The individuals admitted so far have all had intractable behaviour, including severe physical aggression, which has made their care in a variety of settings extremely problematic. The assessment process aims to exclude factors such as mental illness, epilepsy or other physical disorders as causal for this behaviour. If any such disorder is identified, it is fully investigated before an appropriate treatment plan is instigated. Structured communication predominantly using visual material is important for the day-to-day operation of Maple House. The use of digital cameras has revolutionised the production of multiple images for this purpose. Adapting and shaping obsessional behaviour, developing appropriate living skills, improving dietary range, increasing appropriate activity, teaching relaxation and improving communication skills are all integrated into the daily programme. Behavioural analysis to identify the likely triggers for increasing anxiety and potential physical aggression has been facilitated by the structured environment of Maple House.

The future

Maple House is enrolled for future National Autistic Society Autism Service Accreditation involving a



comprehensive audit of 38 individual standards. The staff of Maple House are currently adapting appropriate multi-dimensional measures of quality of life (Felce & Perry, 1995) so as to be meaningful for this patient group. Future publication of these data is planned.

The central premise of the facility is to provide an environment for the comprehensive assessment of individuals with autism who have so far failed in residential settings. This assessment will then inform future residential placements, with the aim of facilitating successful community living. It recognises, however, that individuals with autism are unlikely to have their impairments fundamentally changed by behaviour therapy interventions. Rather, it seeks a detailed understanding of the individuals in order to adapt all aspects of a future environment to their individual requirements. These management principles based on TEACCH should, therefore, be transferable to other settings. Discharge documentation will be produced in a format (not unlike a manual) to allow future carers to plan management proactively, predict behaviour and prevent the recurrence of severe anxiety and physical aggression. This should improve the individual's chances of living in a residential setting.

The current provision is only for individuals with autism and learning disability. Higher-functioning autistic patients, particularly those with a forensic history, may also benefit from a facility that seeks to adapt similar principles to their comprehensive assessment and future management. The need for such specialist services has been reinforced by the flood of referrals received by Maple House since it opened. These have come from across the UK and consist of requests for both diagnostic assessments and admission of individuals who's needs the service responsible is struggling to meet.

Unfortunately, we are unable to respond to this high demand, which has served to remind us of the great lack

of appropriate service provision currently available for these individuals who are, therefore, not having their health needs met.

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