

A Systematic
Review of the
Comparative
Benefits and
Costs of Models
of Providing
Residential and
Vocational
Supports to
Adults with
Autistic
Spectrum
Disorder

*Janet Robertson
& Eric Emerson*



A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with Autistic Spectrum Disorder

*Janet Robertson and Eric Emerson
Institute for Health Research
Lancaster University*

© *Lancaster University 2006*

Funded by The National Autistic Society



LANCASTER
UNIVERSITY

The Institute for Health
Research



Summary

The specific aim of this review was to summarise existing research evidence that may be of value to those responsible for commissioning or providing residential or vocational services for adults with autistic spectrum disorders. The broader aim of the review was to support the development of evidence-based commissioning and practice in the social care of adults with autistic spectrum disorders.

We attempted to identify all research published in the last 25 years that that addressed the *comparative* benefits and/or costs of different ways of providing *community-based* residential and vocational supports to adults with autistic spectrum disorders. We did this by searching key electronic databases and contacting active researchers.

Given that commissioning decisions are inherently comparative, we excluded studies that only described or evaluated one approach to providing support. Given that institutionalisation is no longer a policy option, we also excluded studies of the impact of deinstitutionalisation on adults with autistic spectrum disorders.

Residential Supports

Within the field of intellectual disabilities generally there is a sizeable body of research on the comparative outcomes and costs of models of supported accommodation. For example, a recent systematic review (Emerson, Lobb, Hatton et al., in press) identified 86 papers published *since 1995* that reported the comparative benefits and/or costs of models of supported accommodation for people with intellectual disabilities.

In contrast, comparative research on the benefits and costs of models of residential supports for people with autistic spectrum disorders is remarkably scarce. Indeed, we were only able to identify three studies that had addressed this issue in the last 25 years. The three studies that have been conducted were undertaken in the US, employing small sample sizes, contain a limited range of outcome measures, and contain no information on the cost of supports received. As such, they cannot be considered of any real value to commissioning decisions in the UK.

Vocational Supports

A similar picture is evident when we looked at vocational supports. While there is a substantial literature on superior cost-benefit of supported employment programmes (when compared to sheltered workshops or other day service options) for people with intellectual disability, there is little information available on whether such benefits are also apparent for adults with autistic spectrum disorders.

Most of the available evidence comes from a series of studies undertaken in the UK by Professor Pat Howlin and colleagues. The results of which suggest that supported employment for more able people with autistic spectrum disorders results in significantly higher rates of employment, more appropriate employment, greater job satisfaction and higher employer satisfaction when compared to generic disability employment services, and that such gains are maintained over a significant period of time. Benefits of supported employment for people with autistic spectrum disorders have also been reported by studies undertaken in Spain and the US.

Summary

There exists a remarkable dearth of evidence relating to the comparative costs and benefits of different ways of providing community-based residential and vocational supports for people with autistic spectrum disorders. The lack of any credible evidence-base is a major impediment to the development of any rational approach to evidence-based commissioning and raises the very real possibility that current decisions may result in considerable inefficiencies in the use of resources and the provision of less than optimal supports for people with autistic spectrum disorders.

Addressing the absence of any credible evidence-base in this area must be considered a priority for future research funding regarding the organisation and delivery of health and social care supports for people with disabilities.

The NHS is currently proposing a scoping exercise to identify future research priorities for people with intellectual disabilities. It is **recommended** that commissioning, provider and advocacy agencies use their influence to raise the profile of people with autistic spectrum disorders within this exercise.

It is also **recommended** that commissioning, provider and advocacy agencies (whether on a national or regional basis) explore the possibilities of collaborating to encourage the development of *practice-based evidence*. This could involve, for example, agreements to pool information on the costs and outcomes of residential or vocational services across geographical and sectoral boundaries.

Introduction

This systematic review considers comparative research on the benefits and costs of models of providing residential and vocational supports to adults with ASD. The electronic databases included in searches were: Medline; PsycInfo; Social Sciences Citation Index; Cochrane Library; and Academic Search Premier. The inclusion criteria for publications to be considered in the review were:

1. Comparative studies of models of providing either residential or vocational supports to adults with ASD
2. Quantitative studies
3. Published, in English, since 1980
4. Excluding studies concerned with deinstitutionalisation.

The following search terms were employed (the term “adult* (anywhere)” was added where the preceding combination of terms identified over 200 references):

1. autis* (in ti) AND residen* (in ti)
2. autis* (in ti) AND home* (in ti)
3. autis* (in ti) AND accommodat* (in ti)
4. autis* (in ti) AND support* (in ti) AND adult* (anywhere)
5. autis* (in ti) AND vocat* (in ti)
6. autis* (in ti) AND work* (in ti) AND adult* (anywhere)
7. autis* (in ti) AND day* (in ti)
8. autis* (in ti) AND service* (in ti)
9. autis* (in ti) AND employ* (in ti)

These searches revealed very few studies that were comparative in nature and no two studies employed the same outcome measures. As such, it is not possible to perform any meta-analysis and each of the studies is described in turn.

Residential Supports

Within the field of intellectual disabilities generally there is a sizeable body of research on the comparative outcomes and costs of models of supported accommodation. A systematic review by Emerson, Lobb, Hatton et al. (in press) identified a total of 86 papers published since 1995 that reported the comparative benefits and/or costs of models of supported accommodation for people with intellectual disabilities. Of the post-deinstitutionalisation studies (i.e., those that investigated community-based supported accommodation), 13 (34%) clearly included people with ASD in their samples but none undertook specific analyses on this subgroup. As such, it is not possible to ascertain whether the overall results of these studies apply equally to the subsample of people with ASD.

Comparative research on the benefits and costs of models of residential supports for people with ASD is, in contrast, remarkably scarce. In 1990, the virtual non-existence of research into residential care for people with autism led the *Journal of Autism and Developmental Disorders* to devote a special issue to the residential care of people with autism and related developmental disorders. The issue was intended to stimulate empirical research and as such, articles within the issue were largely descriptive reports of residential programs (e.g. Wall, 1990). Van Bourgondien & Schopler (1990) outlined some of the critical issues that an empirical approach to evaluating the effectiveness of models of residential care should consider including:

- the role of families;
- staff training;
- program components;
- integration with the community;
- goals;
- setting size;
- physical environment;
- costs.

However, since that time little additional research has been published to address these issues.

As noted by Van Bourgondien, Reichle & Schopler (2003) a few studies have demonstrated that specific individual living skills can be taught to adults in residential settings (LaVigna 1983; Smith and Belcher, 1985). There are also a number of case reports that document the difficulties presented by adults with autism in residential settings. For example Brown (1991) used case studies to demonstrate how individualising a person with autism's daily schedule and providing choices increased meaningful participation in daily activities and reduced challenging behaviour. Elliot, Dobbin, Rose and Soper (1994) demonstrated that exercise significantly reduced behaviour problems in 6 men with autism. However, such studies provide no information on the comparative effectiveness of models of residential supports.

Indeed, comparative studies of residential supports for *any* age group of people with ASD are rare. Sherman, Barber, Lorimer, Swinson & Factor (1988) compared the relative effectiveness of residential versus home based and outpatient treatment conditions for young children with autism (5 children in each group). They found that few differences existed, suggesting that for both clinical and economic reasons non-residential approaches with children with autism should be used initially.

With respect to adults, one strand of research in the US has developed and used an instrument called the Environmental Rating Scale (ERS: Van Bourgondien, Reichle, Campbell & Mesibov, 1998) which was specifically developed as an outcome measure for evaluating residential services for people with autism. The ERS measures the degree to which a residential treatment environment is individualised and adapted to meet the needs of a person with autism. In a study designed to assess the psychometric properties of the ERS (Van Bourgondien et al, 1998) results from the ERS from different types of residential settings were compared. The ERS was completed 4 times at 6 monthly intervals for: 10 people living at home with families; 37 in community based homes; and 5 in institutional settings. Of the residential settings, 51% were designed specifically for people with autism. They found significantly higher scores on all subscales and the total score for the autism specific programs compared with both non-autism specific programs and the family home.

Van Bourgondien, Reichle & Schopler (2003) went on to use the ERS in an evaluation of the effectiveness of a model residential program in improving the quality of the treatment program and adaptation of adults and adolescents with autism and severe disabilities. The six people in the treatment group were applicants to a combined residential and vocational training program located on a 79 acre farm, using farming and landscaping as its vocational curriculum. Outcomes for these people were compared to those for 10 people in group homes, 6 in institutions, and 10 in family homes. Outcome measures consisted of: the ERS, which was used to rate the overall degree of programming in the setting; a rating of overall desirability of the setting; a family satisfaction questionnaire; skills in 6 areas (vocational skills, independent functioning, leisure skills, vocational behaviour, functional communication, and interpersonal behaviour); and behaviour problems using both scales and direct observation.

Assessments were done 4 times at 6 monthly intervals. They found that those in the treatment group experienced a higher quality of treatment compared to control settings. Compared to baseline and control measures, they experienced a significant increase in the presence of structure and individualised programming in the areas of communication and social skill development, the use of visual systems to promote independence, the use of developmental planning, and positive preventive behaviour management strategies. The program was also rated as a more desirable place to live. There were no significant changes in skills.

A Final study which includes some very limited comparative information is that of Krauss, Seltzer & Jacobson (2005). This study looked at maternal assessments of residential status for 133 families of adults with ASD living at home or in non-family settings in the US. In 84 families the son or daughter lived in a non-family setting and in 49 families the son or daughter lived with the family. Mothers completed a questionnaire and also took part in an interview. However, a qualitative approach was taken to analysing large sections of the data. Those quantitative results presented are restricted to responses to a 7 point scale rating of how well the current residential situation “works out for you” from 1 (very poorly) to 7 (extremely well). Those who lived with their son or daughter rated the situation less favourably than those living apart from their son or daughter.

In summary, in contrast to the considerable body of knowledge that exists regarding the comparative quality of life related outcomes and comprehensive costs of models of residential supports for people with intellectual disabilities, almost nothing is known about the comparability of residential supports for people with ASD. The very few studies that have been conducted have been in the US context, employing small sample sizes, contain a limited range of outcome measures, and contain no information on the cost of supports received.

Vocational Supports

In parallel with the findings regarding residential supports, the literature on vocational supports for people with autism is limited in comparison to that regarding people with intellectual disabilities generally. As noted by Howlin et al (2005), in the general literature the outcome of supported employment programmes appears to be superior to sheltered workshops or other day service options in terms of: financial gains; wider social integration; increased worker satisfaction; and higher self-esteem (Beyer & Kilsby 1996; McCaughrin et al 1993; Stevens and Martin 1999). However, it cannot be assumed that vocational support strategies that are recommended for people with intellectual disability generally will similarly benefit people with ASD. For example, Muller, Schuler, Burton & Yates (2003) interviewed 18 people with ASD who did not have intellectual disabilities to seek consumer perspectives on strategies for improving vocational services for people with ASD. The results suggest that people with ASD require somewhat different vocational supports to those currently recommended for people with other types of developmental disabilities.

Specialist employment support for people with ASD is almost entirely lacking in the UK. In view of this, Patricia Howlin and colleagues developed and evaluated a dedicated supported employment scheme for people with ASD. The scheme was set up in 1994 and the result of this work is that in the UK, outcome and cost data has been collected for a specialist supported employment service for high-ability adults with ASD (Howlin, Alcock & Burkin, 2005; Mawhood & Howlin, 1999). However, comparative information is restricted to a matched control group of people who had access only to generic disability employment services.

The results of the initial 2 year pilot (Mawhood & Howlin, 1999) indicated that the scheme resulted in significantly higher rates of employment amongst clients than for the matched control group who had access only to generic disability employment services, with 63% finding jobs in the specialist scheme compared to only 25% in the control group. They also found that the type of jobs found (e.g. in administration or computing) were far more appropriate to clients' intellectual and educational levels than in the control group. Salaries and job satisfaction were higher in the specialist group and the service was also viewed positively by employers.

A second study (Howlin, Alcock & Burkin, 2005) examined the success of the programme over 8 years to see how effective the scheme had been in finding work for and supporting individuals in employment. The results indicated that the early level of success in finding employment for clients had been steadily maintained over the 8 years. The proportion of clients in work increased from 63% to 67% and three new centres opened. Of 15 individuals in the original study who could be traced at follow-up, 13 were still in jobs and the other two were receiving support from the scheme. Also, the scheme had begun to meet the needs of those with lower levels of ability. Further, the cost per job found decreased from £6542 in 2000-1 to £4281 in 2002-3. In total, 192 jobs were found over the 8 year period of which 58% were permanent contracts.

Whilst the UK studies indicate the effectiveness and cost of a specialist scheme in finding suitable jobs for people with ASD, the outcome measures do not address the issue of whether finding a job actually improves the quality of life of participants. Ultimately, the concept of quality of life should be vital in the evaluation of such vocational supports, as it has been, for example, in the evaluation of residential supports for people with intellectual disabilities.

A Spanish study (Garcia-Villamizar, Wehman & Diaz Navarro, 2002) does address this issue. They looked at changes in the quality of autistic peoples' lives in either supported or sheltered employment. They looked at 26 people in sheltered workshops (segregated programs with only disabled co-workers) and 21 people in supported work where all jobs were located in the community with a job coach assigned to each worker with autism. The Quality of Life Survey was used to look at environmental control, community involvement, and perception of personal change. Each person with autism (or their job coach if they were non-verbal) was interviewed in 1996 and 2000. They found that the quality of life of those in the sheltered workshop group did not change over the 5 years. In comparison, the supported employment group improved its global quality of life, environmental control, and perception of personal change. However, there was no change in community involvement. They conclude that supported employment is more effective in improving the quality of life of people with autism than more conventional sheltered workshops.

A final study regarding vocational supports that includes a comparative element is that of Schaller & Yang (2005). This US study looks at the issue of competitive employment. They examined differences between people with

autism who received services for competitive employment without provision of supported employment, and people with autism who received supported employment services. Participants were 450 people with autism who received services for competitive employment and 365 people with autism who received supported employment services in the Rehabilitation Services Administration (RSA) database for 2001. No other types of employment (e.g. sheltered workshops) were included.

They found that successful closure rates in competitive employment were 58.4%, compared to a supported employment closure rate 75.3%. Those in competitive employment worked an average of 27.19 hours a week, compared to 22.21 in supported employment. Weekly earnings in competitive employment were \$205.31 compared to \$138.35 in supported employment. The mean cost of services for those successfully closed in competitive employment was \$3,341.14 compared to \$6,882.46 in supported employment. Hence, whilst there was an higher successful closure rate in supported employment than in competitive employment, supported employment had an higher average case service cost, resulted in less hours work per week, and lower wages than for those in competitive employment.

In summary, a very small amount of information exists on the outcomes and costs of vocational supports for people with ASD. However, with the exception of one Spanish study, outcome measures consider only basic issues such as success in job finding and wages rather than broader quality of life issues. Further, in the UK studies the comparative element is restricted to people with ASD receiving generic disability employment services rather than comparison to alternative models of providing specialist vocational support to people with ASD.

References

- Brown, F. (1991). Creative daily scheduling: A nonintrusive approach to challenging behaviors in community residences. *Journal of the Association for Person with Severe Handicaps*, **16**, 75-84.
- Elliot, R., Dobbin,, A., Rose, G., & Soper, H. (1994). Vigorous aerobic exercise versus general motor training activities: effects on maladaptive and stereotypic behaviors of adults with both autism and mental retardation. *Journal of Autism and Developmental Disorders*, **24**, 565-576.
- Emerson, E., Lobb, C., Hatton, C., Noonan Walsh, P., Bradley, V., Schalock, R. & Moseley, C. (2006). *The comparative outcomes and costs of models of supported accommodation for people with intellectual disabilities: a systematic review of the evidence-base*. Institute for Health Research, Lancaster University.
- García-Villamizar, D., Wehman, P. & Diaz Navarro, M. (2002). Changes in the quality of autistic people's life that work in supported and sheltered employment. A 5-year follow-up study. *Journal of vocational rehabilitation*, **17** (4),309-312.
- Howlin, P, Alcock, J. & Burkin, C. (2005). An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism*, **9** (5), 533-549.
- Kilsby, M. & Beyer, S. (1996). Engagement and interactions: a comparison between supported employment and day service provision. *Journal of Intellectual Disability Research*, **40**, 348-358.
- Krauss, M.W., Seltzer, M.M. & Jacobson, H.T. (2005). Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, **49**, 111-124.
- La Vigna, G. (1983). The Jay Nolan Center: A community-based program. In E. Schopler & G. Mesibov (eds.), *Autism in adolescents and adults* (pp381-410). New York: Plenum Press.
- Mawhood, L. & Howlin, P. A. (1999). The outcome of a supported employment scheme for high-functioning adults with autism or Asperger syndrome. *Autism*, **3** (3), 229-254.
- McCaughrin, W., Ellis, W., Rusch, F. & Heal, L. (1993). Cost effectiveness of supported employment. *Mental Retardation*, **31**, 41-48.
- Müller, E., Schuler, A., Burton, B. & Yates, G.B. (2003). Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*, **18** (3), 163-175.

Schaller, J. & Yang, N. (2005). Competitive employment for people with autism: Correlates of successful closure in competitive and supported employment. *Rehabilitation Counseling Bulletin*, **49**, (1), 4-16.

Sherman, J., Barker, P., Lorimer, P., Swinson, R. & Factor, D. (1988). Treatment of autistic children: Relative effectiveness of Residential, Out-patient and Home-based interventions. *Child Psychiatry and Human Development*, **19** (2), 109-125.

Smith, M. & Belcher, R. (1985). Teaching life skills to adults disabled by autism. *Journal of Autism and Developmental Disorders*, **15**, 163-175.

Stevens, P. & Martin, N. (1999). Supporting individuals with intellectual disability and challenging behaviour in integrated work settings: on overview and model for service provision. *Journal of Intellectual Disability Research*, **43**, 19-29.

Van Bourgondien, M.E. & Schopler, E. (1990). Critical issues in the residential care of people with autism. *Journal of Autism and Developmental Disorders*, **20** (3), 391-399.

Van Bourgondien, M.E., Reichle, N., Campbell, D. & Mesibov, G. (1998). The Environmental Rating Scale (ERS): a measure of the quality of the residential environment for adults with autism. *Research in Developmental Disabilities*, **19** (5), 381-94.

Van Bourgondien, M.E., Reichle, N. & Schopler E. (2003). Effects of a model treatment approach on adults with autism. *Journal of Autism and Developmental Disorders*, **33**, 131-140.

Wall, A.J. (1990). Group homes in North Carolina for children and adults with autism. *Journal of Autism and Developmental Disorders*, **20** (3), 353-366.