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The Impact of a Health Check on the Quality of Life of People with Learning Disabilities and their Carers

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DEDICATION

For Alessandro Bovone, Ann, Peter, Winifred and Owen Baxter

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SUMMARY

This study explored the effect of a health check on the quality of life of patients with intellectual disabilities, perceived health of patients and carers and carer stress. Quality of life indicators included abilities, challenging behaviour, mental health, community participation and involvement in activity.

A primary care identified population of 190 people with intellectual disabilities and their carers was divided into two groups. Quality of life data were collected at baseline, once for the experimental group and twice for the control group, after a six-month period to control for extraneous variables. Health checks were conducted for all subjects by primary care teams and post-intervention data were collected four months later. Data were also examined to investigate whether residence type, subject characteristics or health needs being identified influenced any intervention effect.

Little impact was evident on any of the variables measured, although family home subjects and carers of subjects without challenging behaviour reported a reduction in levels of strain at post intervention. Despite the limited intervention impact on quality of life, the health checks identified a range of health needs ranging from impacted earwax to breast cancer. In the light of these findings, the use of standardised quality of life scales to measure effects of changes in individuals' health status is discussed. The health needs identified at the health check highlighted the importance of conducting health promotion with this population, and recommendations are given for strategic use of health checks as one component of the health promotion measures used within primary care.

The Impact of a Health Check on the Quality of Life of People with Learning Disabilities and their Carers

1.0 Introduction

As community based primary health care teams become established as the main health care providers for individuals with a learning disability, they also become the sole access route to secondary and specialist care for this population (Kerr, Fraser, & Felce, 1996; Starfield, 1994). This system of care, which is used for the general population, is a responsive rather than a proactive approach, relying heavily on the ability of the patient to contact and communicate with the general practitioner and other members of the primary health care team. People with learning disabilities have higher health care needs than the general population and experience additional barriers to accessing health care (Beange & Bauman, 1991; Howells, 1986; Whitfield, Langan, & Russell, 1996; Wilson & Haire, 1990). Government documents highlight a need for general practice to address the possible deficiency in caring for such a vulnerable population and have advocated health checks among the recommendations (Learning Disability Advisory Group, 2001; Department of Health, 2001). Although research indicates that health checks are successful in identifying unmet need in learning disabled individuals, their impact in terms of quality of life has, as yet, not been explored (Martin et al., 1997; Webb & Rogers, 1999). The effect on carers of introducing health checks also warrants further investigation, due to the high level of responsibility placed on them regarding the individual's health (Langan et al., 1994; Ward, 2001). These issues are now explored in more detail.

1.1 Health Issues

People with learning disabilities suffer from the same health issues as the general population, and from conditions that have a higher prevalence in learning disabled individuals such as epilepsy, mental health and sensory impairment (Beange et al., 1995; Kappell et al., 1998; Turner & Moss, 1996). Additional health problems that are of concern for the learning disabled population are: respiratory problems (Chaney et al., 1979; Patja et al., 2000), dental problems (Kendall, 1992b) incontinence (Cooper, 1998a) and being underweight (Springer, 1987; Wood, 1994). Some of the key health issues of individuals with a learning disability and with specific syndromes are discussed.

1.1.1 Health issues common in the general population

Although heart disease and cancer are currently at a low prevalence in the learning disabled population (Adlin, 1993; Carter & Jancar, 1983; Cooke, 1997), this is likely to change to some extent with the move to the community where individuals have less restricted lifestyles (Carter & Jancar, 1983; Moss & Turner, 1995) and therefore are more at risk of adopting the habits and lifestyle of the general population with the associated health risks involved, such as smoking, use of alcohol and obesity (Adlin, 1993; Burtner et al., 1995; Moss & Turner, 1995; Rimmer et al., 1993). In addition, people with a learning disability are living longer than before and therefore more likely to experience the morbidities that occur in later life (Holland, 2000; Kappell et al., 1998; Patja et al., 2000). This is particularly true of individuals with mild intellectual disabilities who are now surviving into old age (Patja et al., 2000; Puri et al., 1995). Some common health issues in the general population are outlined here with the health implications for learning disabled individuals.

Obesity

Obesity has a range of associated health problems including heart disease, some forms of cancer, hypertension, diabetes and respiratory problems (Burkart et al., 1985; Bell & Bhate, 1992; Moss & Turner, 1995; Turner & Moss, 1996). People with learning disabilities may have more difficulties with maintaining a healthy weight due to additional morbidities such as physical handicaps, the side effects of medication, dependence on others to monitor diet, and less access to information on a healthy lifestyle (Jackson & Thorbecke, 1982; Springer, 1987; Simila & Niskanen, 1991; Bell & Bhate, 1992; Wood, 1994). Currently one fifth of the general population in Britain is estimated to be obese (19% of males and 21% of females), however, within the learning disabled population, higher rates have been identified for females in community populations of 34.6%, with similar rates found for males of 19.1% (Bell & Bhate, 1992; Office of National Statistics, 2001).

Prevalence rates of obesity, however, do need to be treated with caution due to problems of definition and methodological issues. The variation of measurement tools used (e.g. height and weight tables, tricep skinfold thickness) and the tendency for many researchers and clinicians to use the terms 'overweight' and 'obese' interchangeably has made prevalence rates confusing (Burkart et al., 1985). Caution also has to be taken when using standard measures taken from other populations, as differences may occur in body size and growth rate; particularly in the case of people with learning disabilities, whose physical make up may be atypical (Polednak & Auliffe, 1976; Burkart et al., 1985; Moss & Turner, 1995).

With these considerations in mind, the evidence does suggest that some in the learning disabled population could be particularly vulnerable to becoming obese due to certain characteristics. Firstly, studies of learning disabled populations have highlighted a noticeably higher rate of obesity among females than males (Fox & Rotatori, 1982; Burkart et al., 1985; Emery, Watson J, Watson, Thompson, & Biderman, 1985; Simila & Niskanen, 1991; Bell & Bhate, 1992; Rimmer et al., 1993). Secondly, there has been evidence to suggest that obesity may be more of a problem for individuals living in the community than those residing in institutions, (Rimmer et al., 1993) particularly those in family homes (Emery et al., 1985; Prasher, 1995; Rubin, et al., 1998). Finally, a higher proportion of individuals with mild or moderate learning disabilities were identified as obese compared to more severely disabled individuals (Fox & Rotatori, 1982; Rimmer et al., 1993) though some studies have questioned this association (Emery et al., 1985; Prasher, 1995).

Evidence has suggested that lack of knowledge on nutrition may not be the issue, as obese individuals within the learning disabled population have been found to possess greater knowledge on healthy eating and nutrition than their non-obese counterparts (Golden & Hatcher, 1997). However, the reliance on others to monitor diet may be an important factor, as there has been some evidence of success with parental involvement in behavioural weight loss programs (Jackson & Thorbecke, 1982). Moreover, work in community samples has identified some association between homes with less restrictive environments (i.e. less formal procedures for staff support of residents, no evidence of activity planning) and obesity (Robertson et al., 2000).

Heart Disease and Abnormalities

The learning disabled population (apart from those with Down's Syndrome) is generally believed to have fewer risk factors linked to heart disease due to lifestyle i.e. less access to alcohol and cigarettes (Adlin, 1993; Moss & Turner, 1995). However, as already stated, the move to the community has increased the freedom of the learning disabled population, which is emphasised by the high levels of smoking among those with mild and moderate learning disabilities described in studies in the USA and Australia, which were at least comparable to the general population (Burtner et al., 1995; Tracy & Hosken, 1997). Currently, in the UK, the use of alcohol and cigarettes is low in the learning disabled population but the risk of obesity is high (Edgerton, 1986; Lawrenson et al., 1995; Robertson et al., 2000). The strong relationship between heart disease and obesity suggests that, as rates of obesity continue to rise within the population, so does the risk for heart problems (Wells et al., 1997). Carter & Jancar (1983) noted that deaths from myocardial infarction rose to 8% in the period of 1976-1980 from less than 1% in the years 1930-1950. A study in the USA of adults with learning disabilities, which measured blood lipids, obesity and smoking, found that 23% were considered borderline high risk and 17% were at high risk of cardiovascular disease (Rimmer et al., 1994). Logically, as the learning disabled population is given more freedom and choice in the move to the community, the risk for heart disease is likely to increase to rates more similar to the general population.

As would be expected from the normal aging process, cardiovascular disorders are found at higher rates in the elderly (Schrojenstein Lantman-de Valk et al., 1997; Cooper, 1998a) . Studies have found that, amongst the elderly learning disabled, the prevalence of cardio and cerebrovascular disease is similar to that of the general population (Evenhuis, 1997). People with Down's Syndrome are at particular risk from heart problems both from their vulnerability to heart defects from birth and from their susceptibility to premature aging (Tubman et al., 1991; Nespoli et al., 1993). Rates have been reported of 26.7% for mitral valve prolapse, 13.3% for aortic regurgitation and 40-46% for congenital heart disease in people with Down's Syndrome (Tubman et al., 1991; Van Allen et al., 1999).

Cancer

Cancer, although a major health issue in the general population, has not been of such concern for learning disabled individuals, which could be due to the differences in life expectancy, particularly for the more severely disabled. In a study by Carter & Jancar (1983), cancer only accounted for about 15% of deaths in institutionalised population although rates were found to show an increasing trend over time, from 10% in 1967 to 15% in 1980 and 17.5% in the years of 1976-1985. The types of cancer found in the learning disability population are also notable, as cancers of the gastro intestinal tract are more common and the breast and prostate cancers much less common (Cooke, 1997). A recent study has highlighted the number of deaths due to stomach cancer and suggested that the high rates of helicobacter pylori found in institutional populations may be a factor (Duff et al., 2001). Increased independence, especially among those with milder learning disabilities, may affect these differences, as individuals may begin to adopt a lifestyle which may place them at greater risk (Moss & Turner, 1995). Greater freedom and choice may lead to higher levels of smoking, use of alcohol and obesity, all of which may increase the risks of having cancer.

1.1.2 Associated disabilities common in the learning disabled population

Disabilities common in the general population that have a greater prevalence in the learning disabled population include sensory impairment (Cooke, 1989; Howells, 1986), mental illness (Cooper, 1997) and epilepsy (Smith, Defalla, & Chadwick, 1999). As epilepsy and mental illness carry with them increased mortality, learning disabled individuals with these illnesses can be particularly vulnerable (Morgan, Scheepers, & Kerr, 2001; Puri et al., 1995). The prevalence in the learning disability population of these associated disabilities and their influence on the health of the individual are outlined below.

Sensory Impairment

There are high rates of sensory impairment in populations of people with learning disabilities when compared to the general population. This difference has been reported in Australia (Beange & Bauman, 1991), Denmark (Warburg, 1994), the Netherlands (Schrojenstein Lantman-de Valk et al., 1997) , USA (Kappell et al., 1998) and in the UK (Cooke, 1989; Howells, 1986) and indicates a prevalence for visual impairment of between 15-20% (not including those with Down's Syndrome) against 1.5% in the general population and for impairment of hearing, a rate of 12.3-24% compared to 10% in the general population (Harris, 1978; Tielsch et al., 1990).

A study of a hospital population of individuals with learning disabilities in the UK found that over half of adults had 1 or more eye abnormalities (Aitchison et al., 1990), while a study of an activity centre in the USA discovered an eye abnormality in one third of individuals (Sacks et al., 1991). People with severe or profound disability are more likely to be affected by visual impairments than more able individuals with a learning disability and therefore need appropriate screening (Kwok et al., 1996; McCulloch et al., 1996). Research has suggested that the visual impairment in the severely handicapped is largely due to optic nerve or cortical dysfunction, which may have an association with the presence of epilepsy and or cerebral palsy (Warburg, 1994; McCulloch et al., 1996).

Practitioners who are responsible for an individual's care may often rely on carer report of any difficulties with sight or hearing. However, research findings have suggested that professional testing is needed to assess accurately whether the individual has sensory impairment or not, as carers can both fail to predict sensory impairment when it is present and wrongly identify it in non-impaired individuals (Wilson & Haire, 1990; McCulloch et al., 1996). Similarly, a study in Denmark found that in estimates of visual impairment caregivers and clinicians agreed in only one third of cases (Warburg, 1994). High levels of hearing loss merely due to impacted earwax have also been found in learning disabled populations in the Netherlands and the UK; in some cases, up to seven times higher than would be expected in the general population (Crandell & Roeser, 1993; Evenhuis, 1995b).

Early detection and treatment for sensory impairment has been advocated to reduce further handicap and increase individuals' acceptance and use of sensory aids. It was found in a study of elderly subjects that a quarter had conductive loss of hearing probably caused by unrecognised middle ear infections, which added to the hearing loss occurring with gradual old age (Evenhuis, 1995b). For visual problems, it has been stated that a reduction of excess impairment should be possible by an active diagnostic process at a young age, as causes of excess impairment are often congenital or childhood conditions (Evenhuis, 1995a; Hestnes et al., 1991). Assistive devices such as glasses and hearing aids can help to reduce these impairments and have been used successfully by people with learning disabilities including the elderly (Evenhuis, 1995a; 1995b).

Mental Health

Puri et al., (1995) reported that learning disabled individuals with psychotic disorders other than schizophrenia and mood disorder died significantly younger than those without. Rates of psychiatric illness (not including behaviour disorder) of 16% (Deb et al, 2001), 16.2% (Lund, 1985) and 32.8% (Cooper, 1997) have been identified in the learning disabled population, which are above those found in the general population of 14% (The National Assembly for Wales, 1999). For elderly individuals with a learning disability, the rate of psychiatric illness increases to 53.8% as higher levels of dementia, generalised anxiety disorder and depression are found in older populations (Cooper, 1997). Higher rates of psychiatric illness are often reported due to the inclusion of behaviour disorder (Prosser, 1999), which increases the prevalence rate by 11-15% (Cooper, 1997; Lund, 1985). The relationship between behaviour problems and mental illness can cause confusion with carers sometimes reporting the individual to have a behaviour disorder when in fact psychiatric illness is present (Cooper, 1998b). In addition, abnormal behaviours have been found to mask the symptoms of underlying dementia in the elderly and have also been shown to be associated with the prevalence of psychiatric symptoms, particularly depression (Aylward et al., 1997; Moss et al., 2000).

Epilepsy

Studies of child and adult learning disabled populations have suggested that between one quarter and one third of individuals will have epilepsy, in comparison to 1% or less in the general population (Richardson et al., 1981; Mariani et al., 1993; Branford et al., 1998; The National Assembly for Wales, 1999; Lewis et al., 2000). Prevalence rises as the degree of learning disability increases, with those with severe intellectual impairment showing the highest rates for epilepsy (Richardson et al., 1981; Corbett, 1993; Mariani et al., 1993). Epilepsy has been found to reduce life expectancy in individuals with all degrees of learning disability (Patja et al., 2000; Morgan et al., 2001). The condition is also more complex within the learning disabled population due to the presentation of multiple seizure types and the high severity of epileptic seizures found in individuals, which still are seemingly resistant to treatment (Branford et al., 1998; Tobias, 1994). Difficulties in the diagnosis of epilepsy have been highlighted in this population; particularly for individuals with communication difficulties, who may not be able to express the subjective experience of seizures, and for those with movement disorders or stereotyped behaviour, which can falsely mimic some seizure types (Paul, 1997).

1.1.3 Other health issues of concern in the learning disabled population

Issues of particular concern for the more severely disabled include respiratory problems and being underweight, as these can prove a serious risk to health for these individuals (Chaney et al., 1979; Kennedy et al., 1997; Patja et al., 2000). Dental problems and incontinence, although not life threatening, may have a noticeable effect on an individual's quality of life and have been recognised to have a high prevalence in the learning disabled population as a whole (Shaw et al., 1989; Kendall, 1992a; Beange et al., 1995; Cooper, 1998a)

Underweight

People who are underweight are vulnerable to recurrent food aspiration and respiratory infections, while being severely underweight can put an individual at risk of malnutrition (Kennedy et al. 1997). The research to date has indicated that low weight in the learning disabled population is strongly related to difficulties in feeding (Simila & Niskanen, 1991; Wood, 1994). Reliance on others to be fed, soft diet, food regurgitation and immobility are associated with low weight and, thus, it is often the more disabled individuals who are more at risk (Springer, 1987; Wood, 1994). Kennedy et al., (1997) found that the more severe the feeding difficulty the greater the degree of under nutrition, and that of a group of individuals with learning disabilities and neurological handicaps over two thirds were underweight. Similarly, Springer (1987) found that half of children with nutritional problems were also diagnosed as having seizures and cerebral palsy. A study investigating individuals with nutrition and feeding problems found that they had normal protein levels but a reduced energy intake (fat and carbohydrates), which was difficult to increase due to their swallowing difficulties (Kennedy et al., 1997). Research has suggested that the weight distribution of the population of people with learning disabilities has a tendency to be clustered at the two ends of the scale, with the problem of obesity at one end and under nutrition at the other (Simila & Niskanen, 1991; Wood, 1994) As some research has indicated that this polarisation is more marked outside of institutional care, nutritional issues may be of particular concern in community settings (Wood, 1994).

Respiratory Disease

Previous studies of learning disabled hospital populations have identified respiratory disease as the cause of death in approximately half of cases, compared to about 8% in the general population (Carter & Jancar, 1983; Hollins et al., 1998). A more recent study looking at a large, nation-wide sample in Finland, however, identified the percentage dying from respiratory disease at 22%, which was lower than the number of deaths due to cardiovascular problems (Patja et al., 2000). Rates of mortality from respiratory disease have been found to be considerably higher for individuals with severe learning disabilities than those with mild or moderate learning disabilities (Chaney et al., 1979; Patja et al., 2000). Those who are immobile, have additional disabilities, have problems with food aspiration or who are underweight are more at risk (Chaney et al., 1979; Kennedy et al., 1997).

Dental Disease

Studies have shown that people with learning disabilities have high levels of poor oral hygiene, gum disease and a high prevalence of calculus (Shaw et al., 1989; Kendall, 1992a). Research on the manual dexterity of individuals with learning disabilities has found no relationship with oral health, suggesting that it is not the physical capability of individuals that is influencing the low levels of oral health found in the learning disability population (Shaw et al., 1989). It has been suggested that the population should not be looked at as a whole with regard to dental treatment as differences have emerged in regard to different groups of learning disabled individuals. For example, in a comparison of day centres, the more able individuals were found to have better dental hygiene, less gum inflammation, more fillings and fewer extractions, although they were more likely to have untreated caries, whilst the less able were more likely to have had extractions (Kendall, 1992b). Likewise, adults living in the community in family homes have been found to have significantly more untreated decay and poorer oral hygiene than those living in staffed homes (Tiller et al., 2001).

Some forms of medication may cause periodontal problems in individuals. For example, phenytoin, an anti epileptic, and, thus, of high use in the learning disabled population, has shown an association with gingivitis (Majola et al., 2000). Although previous studies have suggested that individuals with learning disabilities receive less restorative care than others, more recent work is indicating a positive trend that is more in line with the general population (Kendall, 1992a). Indeed, prevalence of tooth decay and loss of teeth has been found not to be particularly high when compared with to the UK population (Kendall, 1992a). However, the problem of reluctance on the part of the individual with a learning disability to accept the care of a dental practitioner has been highlighted (Pratelli & Gelbier, 1998).

Incontinence

In a study population of learning disabled adults in Sydney Australia, 13% were found to have a problem with faecal or urinary incontinence (Beange et al., 1995). Rates of urinary incontinence in learning disabled individuals in the UK have been found at 27.4% for those aged 20-64 and 49.3% for those 65 and above (Cooper, 1998a). Incontinence can be a major difficulty for the individual and carers, and becomes an increasing problem as individuals reach their later years with increased sensory impairment and mobility problems making the situation worse. In a study of elderly people with intellectual disability, incontinence was related in all cases to severe intellectual disability, severe mobility impairment, advanced dementia and advanced Parkinson's disease (Evenhuis, 1997). Incontinence can occur as challenging behaviour in a response to trauma, or as a learned behaviour (Stanley, 1996). In some individuals, incontinence will be as a result of the person's disability, however, the sudden presence of symptoms of incontinence in an individual could be due to infection or an indication of other morbidities (Lennox & Beange, 1999).

1.1.4 Health issues associated with specific syndromes

As well as the high proportion of physical and psychiatric problems found in individuals with a learning disability, there is also evidence of other health needs, many of which are associated with specific syndromes. For example, people with Down's Syndrome have a higher incidence of leukaemia, thyroid problems, skin disorders, musculoskeletal conditions, respiratory problems and Alzheimer's disease (Mani, 1988; Collacott et al., 1992; Adlin, 1993; Van Allen et al., 1999). Individuals with Down's Syndrome are also at notable risk from heart problems, both from their vulnerability to heart defects from birth and also due to their susceptibility to premature aging (Adlin, 1993; Tubman et al., 1991). Other syndromes that are known to have an association with heart defects are Noonen Syndrome (pulmonary stenosis, atrial septal defect, hypertrophic cardiomyopath), Prader Willi Syndrome (rhabdomyomata of the heart and arrhythmias) and Fragile X Syndrome (mitral valve prolapse) (Udwin & Dennis, 1995). People with Fragile X Syndrome also have a vulnerability to central nervous system dysfunction and epilepsy (Hangerman, 1995).

There are also psychological and behavioural problems associated with different syndromes, for example: self injurious behaviour in people with Cornelia de Lange Syndrome; insatiable hunger drive leading to obesity in people who have Prader Willi Syndrome, and inappropriate laughter in Angelman Syndrome (Summers et al., 1995; Udwin & Dennis, 1995; Clarke et al., 1996). Clinical populations have also been found to have associated dental abnormalities such as in Angelman's Syndrome, where prognathism and deformation of primary dentition is common and the high arched palate and dental overcrowding of individuals with Fragile X (Udwin & Dennis, 1995).

Fragile X, Noonen Syndrome and Down's Syndrome have all been found to have particular associations with hearing impairment (Brookes et al., 1972; Keiser et al., 1981; Udwin & Dennis, 1995), which for individuals with Fragile X and Noonen Syndrome, is often due to the high prevalence of otitis media (chronic inflammation of the middle ear) (Udwin & Dennis, 1995; Hangerman et al., 1987). A high prevalence of visual problems among individuals with Down's, Prader Willi and Noonan syndrome (Udwin & Dennis, 1995) has been shown, with elderly individuals with Down's Syndrome showing a prevalence of visual impairment 6-7 times higher than the elderly non learning disabled (Schrojenstein Lantman-de Valk, 1994). The poor visual acuity in Down's Syndrome populations has been attributed to physiological changes in the visual cortex at a young age (Woodhouse et al., 1996).

1.2 Barriers to care

Clearly, there is substantial evidence to suggest that people with learning disabilities often require more attention to their health. However, in practice, they receive a similar amount to that experienced by the general population (Wilson & Haire, 1990; Whitfield et al., 1996). Studies worldwide have found a high number of untreated common conditions amongst patients with learning disabilities (Howells, 1986; Wilson & Haire, 1990; Beange & Bauman, 1991; Webb & Rogers, 1999) and a low level of health promotion and preventative care when compared to the general population (Beange et al., 1995; Kerr et al., 1996; Whitfield et al., 1996). A number of barriers have been identified, such as physical disabilities (Minihan et al., 1993; Chambers et al., 1998), communication difficulties (Wilson & Haire, 1990; Beange et al., 1995) and behavioural problems (Minihan & Dean, 1990). Physicians' lack of confidence and specialist knowledge in the area of learning disabilities (Lennox et al., 1997; Stanley, 1998) have also been highlighted as possible obstacles to care, as well as the additional time and resources required by some learning disabled patients (Eyre, 1996; Stein & Ball, 1999). These possible barriers are now briefly discussed.

1.2.1 Physical barriers

Globally, people with learning disabilities are usually poorer and often dependent on social systems of care for their finances (Beange, 1996). They are unlikely to have a personal means of transport and will often need to be taken to visits for health care. Lack of mobility can present difficulties in physically accessing health services, although individuals may be able to use social systems of care for transportation and assistance during appointments or treatment. Chambers et al. (1998), in a study of the care of intellectually disabled patients moving into the community, found that doctors believed that additional home visits for these patients were due to the unavailability of staff to assist individuals in attending the surgery. However, in a study of physicians in the USA, it was found that 12% of their offices were inaccessible to their patients with mobility problems (Minihan et al., 1993).

Studies have indicated rates of immobility in learning disabled populations of 10% (Kiernan & Moss 1990), 13% (Lowe & Felce, 1995b) and 18% (McGrother et al, 1996), with rates increasing in populations of older individuals with a range from 23% to 32.1% (Cooper, 1998a; Hand, 1994; Haveman et al, 1989). Lack of mobility, in addition to presenting problems in accessing services can make physical examinations more difficult. The range of joint motion has been shown to decrease in healthy people as they age (Heikkinen, 1998; Schultz, 1992) which could make medical procedures uncomfortable. Levels of arthritis have been identified, ranging from one fifth to a half of the population of older individuals with a learning disability (Hand, 1994; Moss et al., 1993; Cooper, 1998a). Maintenance of acquired skills through the use of assistive devices can enable patients to be more independent, and early intervention or treatment of mobility impairment can, in addition, be preventative, by reducing the risk of secondary illness and mortality for individuals (Maaskant & Haveman, 1989; Evenhuis, 1997).

1.2.2 Difficult Behaviour

The prevalence of behaviour problems that obstruct physicians in examining or treating a patient is difficult to judge. There are various methods for measuring challenging behaviour e.g. (Lowe & Felce, 1995a; Qureshi & Alborz, 1992) which take account of behaviours that are difficult for others to tolerate (e.g. stereotypic behaviour, sexually inappropriate behaviour) or that cause harm to the individual, others or property. Behaviours classed as 'challenging' by carers or community teams because they impinge on the individual's activities (e.g. severe stereotypic behaviour), may not prove an obstacle for physical examination. Likewise, a usually compliant individual may be extremely distressed by a visit to a physician and express this inappropriately, making an examination virtually impossible. Minihan & Dean (1990) found 20% of learning disabled patients could only be examined or treated after supportive measures such as pre-medication or pre-visits for desensitisation. Rates of challenging behaviour in populations of people with learning disabilities have been found at around 17% in the UK (Qureshi & Alborz, 1992). Levels of challenging behaviour in general have been found to reduce with increasing age (Moss, 1991), although other studies have showed aggressive behaviour and behaviour disorders to be persistent throughout the lifespan (Day, 1987; Davidson et al., 1999; Cooper, 1998b). Thus, challenging behaviour could still prove to be a barrier to care as individuals move into their later years.

Patients with a psychiatric illness may also demonstrate problem behaviour that could obstruct care and an association has been identified between patients exhibiting challenging behaviour and prevalence of psychiatric symptoms, particularly depression (Moss et al., 2000). Problems in interpreting a person's behaviour, due to unusual response patterns (Lennox et al., 1997) and distinguishing between fear of a medical procedure and a patient's legal right to refuse treatment (Minihan et al, 1993) have been highlighted as possibly causing difficulties for physicians. Only one in five primary care physicians reported that they felt well prepared to handle a patient with intellectual disabilities refusing to cooperate with treatment or an examination (Minihan et al, 1993).

Although physicians may not feel well equipped to deal with an uncooperative patient, as already discussed, this is likely to be a problem in only 20% of cases (Minihan & Dean, 1990). Indeed, only one fifth of physicians rated the maladaptive behaviours of patients in the office setting as a major obstacle to health care (Minihan, et al 1993), although Lennox et al. (1997) found that maladaptive behaviour in the surgery was not mentioned at all. Howells (1986), however, in a study of an adult training centre, discovered that some parents were deterred from visiting the doctor due to the embarrassing behaviour of their offspring. This indicates that behavioural concerns may be more of a problem for carers, which supports the finding that over half of physicians who were not psychiatrists, reported that they had been asked by a caregiver to treat a patient's behavioural problem (Minihan, 1993).

1.2.3 Communication

People with learning disability are often reliant on their family or carers to communicate their health needs on their behalf. Even when a carer knows the person very well, it still may be difficult detect a health problem when the individual's communication skills are limited. The reliance on carers to communicate health needs has been cited as a major barrier to care. In a study of intellectually disabled adults attending a day centre, Wilson & Haire (1990) discovered that health problems had been over looked in instances when carers believed the person to be in good health. Beange et al. (1995), in a study of a population of adults with intellectual disabilities, found that, despite finding a mean of 5.4 actual medical problems per patient, 65% of patients and 24% of the carers reported no symptoms. It has been noted that people with intellectual disability tended to tolerate symptoms or express them atypically as irritability, inactivity, loss of appetite and sleep, particularly for conditions such as sensory impairment, chest pain, dyspnea, dyspepsia and micturition (Evenhuis, 1997).

Patients with mild learning disability are able to locate pain in the same way as controls according to Bromley et al. (1998) who found that patients with learning disabilities could indicate pain using a body map and photographs. Some patients may be able to inform the physician of their symptoms, but may need some basic aids and additional time to express themselves. Kinnell (1987) has suggested that patients who cannot communicate well may have learned to suppress mention of bodily functions, have limited vocabulary and speech, or may not have been given the opportunity to express themselves, especially if the family is under stress. It is difficult in these situations for the physician to obtain the relevant information, as patients may well have not expressed their discomfort to others. Patients with intellectual disability may also benefit from advice and explanations on procedures from either the physician or their carers. This, unfortunately, may be placing additional and unrealistic demands on the time of the physician. Duckworth et al. (1993), in investigating the skills involved in interviewing people with intellectual disabilities, discuss the difficulty of time constraints when a physician may be forced to ignore the patient in order to elicit information quickly from the carer.

Difficulties with history taking and communication have been highlighted where people with a learning disability cannot speak for themselves or are slow at getting information across, (Lennox et al., 1997; Kerr, 1998). This problem can be exacerbated for patients in residential services if, due to staff turnover, there is no one with adequate knowledge of the patient with whom to communicate (Crocker et al., 1987; Lennox et al., 1997). There is clearly a need for the patient to be accompanied by someone who knows him or her well, although this situation may be difficult for a physician to influence unless there is an existing relationship with the staff group. Accurate medical records, however, can reduce many of the difficulties for the physician and reduce reliance on information that may be unreliable (Crocker et al., 1987).

1.2.4 Confidence and Knowledge

UK physicians have been reported as feeling a lack of confidence in treating people with intellectual disabilities (Lennox et al., 1997; Stanley, 1998). This lack of confidence, however, dropped from 36% to 5% for those who had had some previous specialist training (Stanley, 1998). In a more recent study of GP's, no respondents reported feeling totally confident in treating individuals with a learning disability, however, 45% said they did some of the time and 49% reported feeling confident most of the time (Stein, 2000).

Studies have highlighted the need for specialist care for this population and emphasised the need for contact and good referral paths to other health professionals, and services with expertise in intellectual disabilities (Minihan & Dean, 1990; Strauss & Kastner, 1996). However, problems have been highlighted with the primary care physician's lack of knowledge of the specialist services available and their willingness to contact them (Minihan et al., 1993; Bernard & Bates, 1994; Stanley, 1998) Although an attitude survey by Kerr et al. (1996) showed that physicians valued the learning disability specialist teams, low levels of contact between them and the primary care physicians have been reported (Stein, 2000).

It is acknowledged that specialist knowledge in intellectual disabilities is not accessible to all the health professionals who need it and that it needs to be spread more widely into other areas of medicine and accessible to a range of health professionals (Aspray et al., 1999). Primary care physicians have highlighted the usefulness of practical resources such as handbooks, resource guides, lists of specialist physicians, and policy documents on informed consent (Minihan et al., 1993; Lennox et al., 1997). Of particular concern is a physicians' lack of information on informed consent. In a US study, more than half of physicians reported that they did not know who was authorised to give consent for medical treatment of their intellectually disabled patients (Minihan et al., 1993). Similarly, in a study in the UK, two thirds of physicians were unaware of the correct procedures for consent to treatment for people with intellectual disability, according to English law (Turner et al., 1999).

1.2.5 Additional Time and Resources

With the additional health needs inherent in the learning disabled population there have been indications that, if these are adequately addressed, a higher level of resources is required. Studies have found that patients with intellectual disabilities have higher consultation rates, out of hours visits and contact with specialist services (Eyre, 1996; Stein & Ball, 1999; Morgan et al., 2000). This increased use of services is believed to be even higher for those resettled from long stay institutions where, in some instances, the workload involved was found to be four to five times greater than for the non learning disabled (Chambers et al., 1998; Martin & Martin, 2000). People with intellectual disabilities have also been found to have a higher number of hospital admissions and a greater average length of stay in hospital than the general population (Walsh et al., 1997). However, the mean length of hospital stay reduced to levels comparable with that for the general population when care was coordinated (Criscione et al., 1993). This study found that care coordination (e.g. organising referrals, maintaining and communicating medical record information and assisting and supporting patients to access health care services appropriately) was associated not just with reductions in length of hospital stay, but also with lower readmission rates and hospital charges. McConkey & McAteer (1999) have also highlighted that due to the number and range of different professionals involved with the care of learning disabled individuals, care co-ordination is essential to ensure services are cost effective.

People with intellectual disabilities may well need longer or even additional consultations to address certain medical problems (Chambers et al., 1998). Although this may increase workload initially, early diagnosis and treatment for some conditions could reduce the need for more complicated medical procedures later on, as well as giving obvious benefits for the patient. As previously discussed, the treatment of obesity can reduce the likelihood of cardiovascular problems (Rimmer et al., 1994; Wells et al., 1997), early intervention for sensory impairment or mobility can prevent further deterioration (Evenhuis, 1995a, 1995b; Hestnes et al., 1991; Evenhuis, 1997) and the detection of psychiatric illness or epilepsy are clearly necessary due to the increased risk of mortality (Puri et al., 1995; Patja et al., 2000; Morgan et al., 2001). It has been found that, although patients with disability may fail to report symptoms, conditions can be diagnosed as accurately as for patients in the general population: as long as health professionals use routine diagnostic screenings with a knowledge of risk factors and atypical presentations, in addition to taking account of carer observations (Evenhuis, 1997). The benefits of early detection and treatment in a population of people who have been shown to have a high rate of unmet health needs, has been one of the strongest arguments for the use of health checks with patients with learning disabilities.

1.3 Policy Recommendations for the Health Care of Individuals with a Learning Disability

The government guidance from the NHS Executive and from the Welsh Health Planning Forum, began to highlight some of the issues in addressing the problem of unmet need for people with learning disabilities and to make recommendations as to how these could be addressed by the NHS (Welsh Health Planning Forum, 1992; Lindsey, 1998). A further document by the NHS Executive, 'Once a Day', designed specifically for the primary care teams, sought to give information on good practice with regard to treating people with learning disabilities (Lindsey & Russell, 1999). However, a later study by the Department of Health, 'Facing the Facts', looking at health and social care services, indicated that there were many inconsistencies in health service provision across the country, highlighting a lack of clarity in NHS responsibilities (Department of Health, 1999). Of particular concern was that the individuals most affected by these inconsistencies in services were those with severe or multiple disabilities, the most vulnerable individuals in the learning disabled population.

'Valuing People', the Government White Paper published in 2001, moved a step forward in that it laid out specific targets, strategies and deadlines for social and health services, including the use of 'health care facilitators', 'health action plans' and the registering of all people with a learning disability with a general practitioner to be achieved by 2005 (Department of Health, 2001). This strategy, however, only applies to England. The Scottish Executive and the Welsh Assembly have both published relevant documents highlighting the problems in provision of care but without such specific aims and targets as given in 'Valuing People' (The Scottish Executive, 2000; Learning Disability Advisory Group, 2001, Health Evidence Bulletins Wales, 2000). 'Fulfilling the Promises', the document commissioned by the National Assembly of Wales, has advocated the need for regular health check ups for individuals with learning disabilities and the need for further GP training to be addressed by the year 2010 (Learning Disability Advisory Group, 2001). Thus, although there is recognition by the policy makers of the need to address the deficit in health care for individuals with a learning disability, the specific strategies that will best serve this population are still under investigation.

1.4 The Use of Health Checks

In the absence of an individual being able to request a doctor's care, there is a clear requirement for health care to be proactive rather than responsive. The need for individuals with learning disabilities to have a regular medical examination and general assessment has been recommended by the Royal College of General Practitioners to address the problem of hidden morbidities in this population (Royal College of General Practitioners, 1990). Rates of health promotion for individuals with a learning disability have been found to be generally lower than that for the general population (Whitfield et al., 1996). Annual health checks have been used as a way to address this problem and have been found effective in identifying health needs in Australia (Beange et al., 1995), New Zealand (Webb & Rogers, 1999) and the UK (Martin et al., 1997). Different styles of health checks have been used in these studies with different health professionals conducting them. There are obvious benefits for the health checks to be conducted by the individual's general practitioner; however, studies have indicated the value of nurses conducting health checks (Barr et al., 1999; Hunt et al., 2001). In studies of health checks used for the elderly, it was found that nurses placed a higher value on the use of health assessments, and found a higher level of unmet need than the general practitioners (Chew et al., 1994; Tremellen, 1992).

The benefit of health checks for groups of people with higher health needs has been established for those aged over 75 years. Studies have found that approximately half the individuals receiving health checks had needs identified (Brown & Williams, 1992). No impact on the individual's health status or their vulnerability to stress was found, although the authors did believe there was some evidence to suggest that length of hospital stays were reduced though identifying unmet needs (Tulloch & Moore, 1979). However, an increase in the use of available resources was found in responding to the health needs identified by the health checks (Brown & Williams, 1992; Chew et al., 1994; Tulloch & Moore, 1979). This would agree with the studies of the learning disabled population described above, that indicated a higher use of resources when health needs were adequately addressed (Eyre, 1996; Stein & Ball, 1999; Morgan et al., 2000).

Health checks are successful in identifying unmet health needs in individuals with a learning disability and have been advocated by the Department of Health (Beange et al., 1995; Lindsey, 1998; Webb & Rogers, 1999). However, there has been some debate over which group of health professionals should be primarily responsible for conducting health checks: the primary care team, the community learning disability team or indeed carers with respect to continuous monitoring (Matthews & Hegarty, 1997; Barr et al., 1999; Curtice & Long, 2002). The primary care team has been recommended to consider the use of health checks, probably as it is the means of access to other specialist services. However, despite this studies have reported a reluctance on the part of general practitioners to perform annual health checks without additional remuneration (Lennox et al., 1997; Stein, 2000; Gill et al., 2002).

Once unmet health needs have been identified, the question remains as to whether this will lead to an improvement in the individual's general health and quality of life. The use of quality of life measures to assess the long-term effectiveness of health checks has been suggested because of the strong link between an individual's health and the quality of life they experience (Martin & Roy, 1999). Felce & Perry (1995b) have argued that quality of life is multidimensional and consists of different domain areas (physical well-being, material well-being, social well-being, emotional well-being and productive well-being). These domains are then influenced by objective life conditions, subjective feelings of well-being and personal values and aspirations, which interact with each other and may change as a result of external influences. Thus, an improvement in an individual's health may influence other areas of well-being. For example, Barr et al., 1999, put forward the argument that undetected sensory deficits can have a marked affect on the life of individuals in reducing their ability to learn or maintain a previous level of independence and by making them more vulnerable to accidents. Also, the question still stands as to whether the use of health promotion can lead directly to a reduction in morbidity that will reduce the need for services later on (Cairns, 1995). Researchers have also suggested that, in the particular case of individuals with a learning disability, the effect on the health and well being of the carer and family needs also to be considered (Martin & Roy, 1999).

1.5 The Role of the Carer

The role of the primary carer is an important one when considering the health needs of an individual with a learning disability. As already discussed a number of barriers exist for individuals in accessing health care, which can be reduced to a degree through the support of the primary carer. For some learning disabled individuals, support may involve accompanying them to the surgery or booking an appointment, whereas others may need someone to communicate and give health information to the health professional on their behalf. Carers can thus find themselves as the advocate for the person with learning disabilities and the one responsible for monitoring the individual's health (Langan et al., 1994; Moss et al., 1996; Ward, 2001). Both family and residential carers can also be involved in influencing the social profile of the person with a learning disability in the community, (which could include a general practice surgery) and also may monitor the information given to an individual by others (Shearn & Todd, 1996; Todd, 2000). The role of the carer in influencing the health care of the individual and the impact this may have on carer stress is discussed below.

1.5.1 The carer as the advocate

The primary carer may have to adopt the stance of advocate when dealing with health professionals or other specialised services to ensure that the individual's needs are attended to and that they are receiving the services and care that they require (Langan et al., 1994; Ward, 2001). Without specialised training, health professionals have not been found to adapt their communication skills automatically to meet the needs of an individual with a learning disability (Harper & Wadsworth, 1992). Thus, the carer may need to be present to fill the gap between the communication abilities of both the patient and the health professional. Even when the individual can communicate, there has been shown to be a tendency for the individual to acquiesce to questions put to them, which may emphasise the need for carers to be present (Langan et al., 1994; Perry et al., 2000). Despite this, carers may find the role of advocate problematic and the difficulty for family carers in speaking up for their adult offspring was given as a possible reason for the high number of unmet health needs identified in one study (Howells, 1986). Similarly, in another study of carers' views, although two thirds of carers felt that health screening or health promotion would have been of benefit to the individual, none of them had actually discussed this with the general practitioner (Langan et al., 1994).

1.5.2 The carer as the monitor of the individual's health

Carers are often required to monitor the health of the individual with learning disabilities including checking the person's reaction to medication and informing the health professional of any adverse side effects (Langan et al., 1994). The importance of the involvement of the carer as well as the individual with a learning disability has been highlighted in the diagnosis of psychiatric illness, where researchers found that without the combined interviews of both parties, one third of psychiatric cases would have remained undiagnosed (Moss et al., 1996). In many cases, the health professional will also be reliant on the carer recognising behavioural change that may indicate symptoms of an underlying illness. Research has indicated the importance of taking into account carer observations, as individuals with learning disabilities sometimes tolerate or present symptoms atypically (Evenhuis, 1997).

Both paid and unpaid carers are required to fulfil this role in the life of a person with a learning disability. However there are considerable differences between the relationships the individual has with their own family and with a member of support staff, and, in terms of monitoring the individual's health, it can be seen that family and staffed home carers are skilled in different ways. The family carer is likely to have known the individual for the entire duration of his or her life and, therefore, can give information on childhood illnesses, allergies and so on with considerable accuracy due to the amount of knowledge they have about the person (Ward, 2001). For the paid carers, the opposite is true in that they are unlikely to have known the individual prior to their adult years, but may have received specialised training in recognising illnesses or, possibly, undertaken nurse training; although, since deintsitutionalisation, this is becoming less common (Smith et al., 1996).

There are concerns, however, in the ability of both family and staffed home carers to recognise symptoms and underlying health needs in individuals with a learning disability (Beange et al., 1995; Wilson & Haire, 1990). In one study, it was discovered that psychiatric cases had not been identified by psychiatric services, although the care staff were aware of the symptoms (Moss & Patel, 1993). In addition, studies have suggested that less able residents and those with challenging behaviour receive less time and attention from members of care staff (Jones et al., 1997). In terms of monitoring health care needs, this could be a problem as it is the more disabled who are more likely to have communication problems and suffer from additional health care needs (Chaney et al., 1979; Corbett, 1993). Similarly, as challenging behaviour has been found to mask or confuse underlying symptoms of epilepsy or mental illness, this would suggest that individuals with these conditions might require additional attention to their health (Aylward et al., 1997; Paul, 1997). Higher staffing levels and training in resident activity have been advocated for enhancing staff attention and this has proved effective in addressing the imbalance of attention, to the benefit of more disabled individuals (Jones et al., 1997). Despite these concerns, it has been shown that the majority of carers in family and staffed homes are confident of their ability to monitor the health of the individual in their care (Langan et al., 1994); which, for the foreseeable future, is likely to remain their responsibility.

1.5.3 The carer as the manager of social situations

Managing the social profile of the individual is a difficult task for many residential and family carers. The common tendency to protect the individual from social stigma and in some cases, full knowledge of the meaning of the term 'learning disability' can result in some complex strategies of social management. Shearn & Todd (1996) and Todd (2000) found that family and staffed home carers adopted similar strategies in that they selected social situations where there was less likelihood of the individual being involved in a noticeable or embarrassing event. A visit to the general practice surgery may be viewed as a potentially stressful situation for some carers who may be embarrassed by the behaviour or appearance of their offspring (Howells, 1986).

1.5.4 Causes of stress in family and residential carers

Considering the responsibility and influence that carers have over the well being of the individual, the potential effect of the caring role needs to be recognised. Research has investigated many of the possible factors influencing stress in family and residential carers. Both populations of carers are affected if the individual has mental health or behaviour problems, although the impact has been suggested to be more severe for the family carers (McGrother et al., 1996; Larson & Lakin, 1999). Organisational issues have been shown to have the most effect on the stress of residential staff, whereas the evidence of the effect of resident characteristics is mixed (Sharrard, 1992). Additional strains for family carers are lack of service provision and concerns about their offspring's future well being and health (Harris & McHale, 1989; Quine & Pahl, 1989).

Greater support needs of residents, particularly mental health problems and challenging behaviour, have been found to affect staff turnover within residential homes (Larson & Lakin, 1999). Challenging behaviour has been identified as a source of stress for residential carers, who have been found to develop coping strategies such as 'detachment', taking 'time out' and by obtaining emotional support from other members of staff (Hastings, 1995). However, the literature examining the variables influencing stress in residential carers has indicated that, although resident characteristics can affect the stress levels of staff, organisational issues are thought to be a more signficant factor (Sharrard, 1992; Hatton & Emerson, 1993; Larson & Lakin, 1999). In a study of staff stress in different settings, the demands of residents was cause of stress for staff in a long stay hospital and those in a small group home, but not for staff in a larger community unit, suggesting that organisational factors could influence whether or not residents are a cause of stress (Rose, 1993). In examining the concept of burnout among human service workers, it was suggested that professionals are trained to deal with the difficulties with clients but they do not receive training in organisational issues (Leiter, 1991). However, the former may be an assumption judging by the 40% of care workers who cited challenging behaviour as the area of training they would like to see prioritised (Smith et al., 1996).

The literature investigating the impact of caring for a child with a learning disability has discussed the increased levels of stress experienced by the parents, particularly if the child exhibits problem behaviour (Quine & Pahl, 1989; Sloper et al., 1991; Stores et al., 1998). The presence of challenging behaviour has a noticeable effect on the child's level of dependency, as viewed by the carer, and this has been demonstrated in measuring the level of carer requests for respite help (McGrath & Grant, 1993; Quine & Pahl, 1989). Although research has suggested a decrease in behaviour problems once the individual reaches adulthood (Grant & McGrath, 1990; McGrath & Grant, 1993), the problem for parents of physically managing an adult rather than a child is difficult (Shearn & Todd, 1997). Moreover, the parental role of carer continues well into the adult years and this has been highlighted as one of the major sources of stress for family carers (Todd et al., 1993; Todd & Shearn, 1996a, 1996b; Shearn & Todd, 1997).

In a study of family carers of adults with a learning disability, 40% of female carers reported a limiting health disorder and those suffering from depression were twice as likely to be caring for someone with a behaviour problem (McGrother et al., 1996). Likewise a study based on data taken from the General Household Survey found that carers most at risk from poor health were those caring for a dependent with both physical and mental impairments, and those caring in their own home (Evandrou, 1996). The lack of services for adult carers has been reported with one study finding indicators that carers of adults were receiving less help than carers of children facing similar levels of dependency and behaviour problems (McGrath & Grant, 1993). This warrants particular attention since families' reliance on formal support increases, as the child becomes an adult, due to the reduction of informal support networks (McGrath & Grant, 1993; Todd et al., 1993; Todd & Shearn, 1996b; Hoare et al., 1998). Reports of parents' accounts of their experiences have described some families providing 'round the clock care' due to the unsuitability or unavailability of services (Todd & Shearn, 1996b).

Family carers also have the particular worry of what will happen to the individual with a learning disability once they are no longer able to provide care (Todd et al., 1993). Quine & Pahl (1989), found in a study of family carers, that the greatest concern of carers was the individuals' lack of communication skills; the second was the future for the individual and the third was the offspring's health. Similarly, in another study, the major worry for 83% of mothers was the present and future health and well being of their child (Harris & McHale, 1989). This concern of families with the individual's health is reflected in the work of Conroy (1985), who examined the reactions of family members and institutional staff members to the process of deintsitutionalisation and the perceived medical needs of the learning disabled patients. The study found that families perceived their relative with a learning disability as far more needy of medical care than did the institutional staff members. The authors also cited an earlier study by Keating et al. (1980), using the same sample of family carers, who found that the strongest predictor of family opposition to deintsitutionalisation was the family's perception of the relative's degree of need for medical care. Indeed, the evidence would suggest that the health issues of the individual might have an impact on the carer due to the responsibility created by the caring role. Thus, the evidence suggests that any change in the approach to the health care of individuals with learning disabilities, may also have a noticeable effect on their carers.

1.6 Aims of the Study

Government documents have advocated the use of health checks as a means to address the higher health care needs of the learning disabled population and the barriers to care as outlined above (Department of Health, 2001). Although the effectiveness of health checks in identifying unmet health needs has largely been proven, the impact on the individual of such a proactive health measure has not been investigated. Thus the first research aim of this study was to explore whether having a health check has any impact on the ability level, behaviour, mental health, level of community activity, level of choice, level of physical activity, epilepsy status, or perceived health status of individuals with a learning disability.

The strong relationship and dependency of people with a learning disability on their carers suggests that an intervention which may have an influence on the individual's health could also impact on the well being of the carer. Therefore, the second research aim was to investigate whether the use of health checks has any effect on the stress levels or perceived health status of carers.

The third aim was to explore whether the characteristics of the individual influenced the effectiveness of the intervention, by comparing individuals with and without social impairment, challenging behaviour and mental illness. In addition, any differential impact of having one or more health needs identified as a result of the health check and whether or not these were subsequently treated was also examined.

2.0 Method

2.1 Recruitment and Characteristics of Practices

The 40 general practices that participated in the study came from three health authorities in Wales: Bro Taf, Gwent and Dyfed Powys. The study practices represented 14% of the total number of practices in the health authorities of Bro Taf and Dyfed Powys and 9% of the practices in the Gwent health authority (Table 1). Of the 324 practices on the original health authority lists, 192 (59%) were contacted and 40 (12%) fully participated (Table 1). The initial aim was to recruit 400 patients, to allow for two groups of 150 subjects with a considerable margin for drop out. The number of subjects required in each group was based on a power calculation of the SF-36 that indicated that in order to have an 80% power of detecting a difference of 6 points, two groups of 150 subjects would be needed. The SF-36 was used for the power calculation, as it is an established scale and due to the development of a proxy version could be used to measure the health status of both the subjects and carers. Six points was identified as a relevant change in health status based on the guidance on desirable sample sizes given by the scale author (Ware, 1993).

Although it was estimated from information given by other researchers in the field (Jones & Kerr, 1997) that the primary care teams would identify approximately 10 patients in the average practice, due to the consent process only 5-6 patients per practice were expected to participate. It was also anticipated that a low percentage of the practices contacted would chose to take part in the study, as previous research had suggested that GP's may be reluctant to participate in research that would only benefit a small percentage of their patient list

(Dovey & Webb, 2000). Therefore 10-15% of practices contacted were expected to participate and with an estimate of 65 practices needed (based on 6 patients per practice giving consent), 600 practices would be required to be contacted (from at least 5 health authorities). However, the first 120 practices contacted in Bro Taf taken from the alphabetical health authority list of practices, resulted in 34 practices expressing an interest in participating (25%), which was far higher than foreseen (Table 1). In addition, information gathered from the practices during recruitment suggested that the primary care teams were identifying double the numbers previously calculated and thus recruitment was immediately halted in Bro Taf to ensure patients could be included from the other health authorities. Based on the recruitment rate from Bro Taf, a smaller percentage of practices were contacted from the other health authorities (Dyfed Powys = 28% and Gwent 45%), which introduced the possibility of some bias in the sample of practices but was deemed necessary to prevent an unmanageable number of practices and patients expecting to participate.

Table 1. Practices selected and identified from health authority lists

	Bro Taf	Dyfed Powys	Gwent	Total
Number on health authority list	136	78	110	324
Number selected to be contacted	120 (88%)	22 (28%)	50 (45%)	192 (59%)
Practices initially interested in study	34 (25%)	15 (19%)	17 (15%)	66 (20%)
Practices willing to take part in study	19 (14%)	11(14%)	10 (9%)	40 (12%)

NB. The numbers in parentheses show the number of practices as a percentage of those on the respective health authority lists.

Information on the total number of practices, the number of patients registered, and the Townsend Index Score was collected across each of the health authorities as a whole (Table 2). The Townsend Index gives an indication of material deprivation, based on data relating to unemployment, housing tenure, overcrowded households and car ownership. A positive value indicates relative deprivation when compared with the average (Townsend, 1987). The number of patients registered with practices within each health authority was obtained from data published by the Welsh Assembly (National Assembly for Wales, 2001). The size of the practices in the sample was obtained during recruitment onto the study and the Townsend Index scores were obtained for each practice and for each health authority from the health authority statistical departments (Table 2). The number of practices, size of practice and Townsend score for the health authorities were then compared to the study sample.

In comparing the number of patients registered with the health authorities and those registered with the practices in the study, the sample population represented 28%, 16% and 11% respectively, of the total number of patients registered with the Bro Taf, Dyfed Powys and Gwent health authorities (Table 2). Just under half of the practices in the sample population were recruited from the Bro Taf health authority (number of practices = 19), with just under a third of the total general patient population being covered by these practices (patients registered with practices in study = 209,717). The practices in the sample population showed a larger register size (mean size = 6,831) and a greater level of material deprivation (Townsend Index Score = 5.12) when compared to the Bro Taf health authority practices as a whole (mean size = 5,441 and Townsend Index Score 1.8), suggesting that larger practices from areas of greater deprivation were choosing to participate.

Table 2. Comparison between whole and sample populations for each health authority

	Whole population within health authority	Sample population used for study
Bro Taf		
Number of patients registered in total	739 989	209 717
Number of practices	136	19
Mean size of practice (number of patients registered)	5 441	6 831
Mean on Townsend Index	1.8	5.12
Range on Townsend Index	Unavailable	(-7.50 – 24.9)
Dyfed Powys		
Number of patients registered in total	493 870	82 584
Number of practices	78	11
Mean size of practice (number of patients registered)	6 332	7 508
Mean on Townsend Index	-0.46	-0.45
Range on Townsend Index	(-3.53 – 2.94)	(-3.53 – 1.29)
Gwent		
Number of patients registered in total	571 206	61 301
Number of practices	110	10
Mean size of practice (number of patients registered)	5 146	6 480
Mean on Townsend Index	0	-0.37
Range on Townsend Index	(-9.19 – 9.29)	(-3.01 – 2.27)

From the Dyfed Powys health authority, one sixth of the total general patient population was represented (patients registered with study practices = 82,584) and the practices recruited formed one quarter of the sample population (11 practices). Again, the practices taking part in the study were larger than those across the whole of Dyfed Powys health authority (health authority = 6,332, study = 7,508,) but the level of material deprivation was more or less the same (health authority = -0.46, study = -0.45) and noticeably lower than the Bro Taf practices.

The practices recruited from Gwent health authority covered one ninth of the total general patient population (health authority = 571,206, study = 61,301) and formed one quarter of the practices in the sample population. The sample population practices were again larger (mean size = 6,480) compared to the whole health authority (mean size = 5,146) and the level of material deprivation was similar for both (health authority = 0, study = -0.37). Again the level of material deprivation for both the Gwent health authority and the sample population was noticeably lower when compared to the Bro Taf health authority and sample population.

A member of the research team visited 64 of the practices interested in participating to explain the aims and procedure of the study, as two practices withdrew prior to this visit. The practices were asked to begin identifying their patients with learning disabilities using the first part of an educational package. The package contained basic information on identification of patients with learning disabilities and a flow diagram of methods of identification, which included keyword searches that could be programmed into the practice computer. After the visit, 19 practices declined to participate, a further two practices withdrew when they could not find a sufficient number of learning disability patients on their register and two other practices left due to workload pressures. One practice did not manage to complete the health checks in the required time for the study and therefore was omitted from the final sample.

The 40 participating practices who had identified their patient list of people with learning disabilities were then divided into 2 groups; 20 in the experimental group (Group A) and 20 in a comparison group (Group B). Practices in each group were matched by health authority and, as far as possible, by size and Townsend Index Score, with no significant differences found between the two groups in these respects (Table 3). Approximately half the practices in each group were from the Bro Taf health authority with practices from the Dyfed Powys and Gwent each taking a quarter. The mean size of practice was similar in the two groups (Group A = 6,958, Group B = 6,901), with a higher Townsend Score for the practices in Group B, suggesting a greater level of material deprivation for those practices, although not significantly so.

Table 3. Characteristics of practices on study

	Group A (n=20)	Group B (n=20)
Number of practices from Bro Taf	9	10
Number of practices Gwent	5	5
Number of practices Dyfed Powys	6	5
Size of practice mean (range)	6958 (1339 -15856)	6901 (1606-14700)
Townsend Score mean (range)	1.62 (-7.5 – 24.9)	2.81 (-2.38 – 13.90)

2.2 Recruitment and Characteristics of Patients

Complete datasets were completed for 190 primary care patients from the 40 general practices. The average age of the subjects was 43 years (range 17-86 years) with all subjects aged 18 years or above at the time of the intervention. Although one subject included in the study group was 17 at the time of the baseline data collection, her 18th birthday occurred prior to the administration of the health check by the practice. There was a higher percentage of females (56.8%) than males (43.2%) with just over half living in staffed housing (53.7%). A small percentage of the subjects were living independently (6.8%) and the remainder were resident in family homes (39.5%). Approximately half of the subjects were socially impaired (52.6%) and 37.9% of the subjects also had the triad of social impairment.

There were 102 subjects who were resident in 33 staffed homes, 8 (24.2%) of which were specialist staffed homes (established specifically to cater for people with challenging behaviour), 24 (72.7%) were ordinary staffed homes and 1 was a group home (i.e. not staffed full time). Three quarters (76.7%) of the staffed homes only catered for people with a learning disability, the remainder included other residents without a learning disability who needed staff support. One fifth (19.4%) of the 33 homes catered only for males, one third (32.3%) catered only for females and approximately half (48.3%) were of mixed gender.

Of the 33 staffed homes, one quarter (25%) of the homes employed a senior member of staff who possessed a nursing qualification with one home employing two. None of the non-senior staff were qualified in nursing and three quarters of the houses (75%) had no staff members who possessed any nursing qualifications. Approximately half (48.3%) of the homes had a written control and restraint policy in operation and staff members in over half of the homes (55.2%) had received some training in control and restraint. Over half of the houses (54.5%) had a system of individual planning in place and just under half (48.5%) had a method of involving residents in decision making, including those with communication difficulties. One quarter (25%) used a resident orientated timetabling system that all staff were trained to use and just under two thirds (62.5%) of the homes had a comprehensive system of staff training and supervision.

Ethical approval for the study was obtained from Bro Taf, Dyfed Powys and Gwent health authority ethical committees. Consent was gained from individuals and carers via the participating practices. To preserve confidentiality the primary care teams identified their own patients using information from the research team on how to identify individuals with a learning disability. The primary care teams informed the researchers of the approximate number of patients but not their names and were sent a copy of a pro forma letter on a computer disk, copies of the study information sheets for patients and carers and stamped envelopes with the practice address. Each practice was asked to contact their patients directly to invite them to participate in the research and patients were asked to sign and return a slip at the bottom of the letter to say whether they wished to participate or not, although in some instances the patients contacted the practice directly by telephone. The majority of practices also contacted the patients by telephone if they had not responded to the letter, to check if they wished to participate. Only when the practice knew which patients were interested in taking part in the study, was the research team informed of their names and contact details, and written consent was obtained from those who agreed to participate.

From the 40 practices who fully participated in the study 374 patient names were initially given to the research team. As the research team was not permitted to have the names or information about the people identified by the practice as having learning disabilities who did not wish to participate, it was difficult to calculate whether the practices had identified all their learning disability patients accurately. However, 16 of the 40 practices were able to provide the number of patients they had originally identified as having learning disabilities.

These 16 practices had originally found 361 patients with learning disabilities (including children who did not participate in this study), which gave an average of 23 patients in total per practice. There were no significant differences between these 16 practices and the total study sample with respect to size, health authority, Townsend Index score and total number of patients. Therefore, from this information, it could be calculated that the 40 practices could be estimated to have originally identified 920 patients with learning disabilities.

The average number of patients with learning disabilities identified by the practices participating on the study was compared to the national figures found across Wales as recorded on the social services register (for adults and children). A prevalence rate of 4.2 persons per 1,000 was given for the year 2000 (The National Assembly for Wales, 2001) and can be used for comparison as the majority of the practices identified their patients from May 1999 through to May/June 2000. This means that the average general practice in Wales (based on the average patient register across Wales of 5,763) would expect to have 24 patients with a learning disability who are known to social services (The National Assembly for Wales, 2001). Thus, the practices were able to identify a similar number of patients as those identified by social services, but not necessarily the same patients, as it cannot be assumed that everyone with a learning disability would be on the current social services register.

The number initially identified by the study practices and the national figures includes children, who accounted for 19% of the original study sample. Thus, of the 920 patients estimated that the practices would have found on their registers, it was calculated that approximately 745 (81%) would have been adults. Of the 374 names of adult patients that were given to the research team 3 adults were later found not to have learning disabilities.

The final number of 371 correctly identified patients given to the research team can be compared to the estimated number of 745 that the practices had originally identified from their registers, which would suggest that 49% of those contacted wished to participate in the study. Further detail on the number of "no replies" and negative responses was not available from enough of the practices to draw any further conclusions.

Baseline data were collected on 318 adults who wished to participate in the study (150 in Group 1 and 168 in Group 2) out of the 371 adults who were initially identified by the primary care teams. A member of the research team visited the patients to explain more about the study and obtain written consent to participate from patients and carers. At this stage the study sample decreased by 53, 48 subjects decided not to participate in the study, 1 subject moved house, 1 subject died and baseline data were unavailable for a further 3 subjects (one subject was accidentally omitted, another subject's data went missing, and the third had a health check conducted before data collection was complete).

Complete full datasets were finally obtained for 190 subjects (107 in Group A and 83 in Group B) of the 318 subjects who had participated. There was found to be considerable attenuation in the sample with 128 subjects withdrawing during the course of the study (Table 4). In Group A, 43 subjects withdrew resulting in a final number of 107 and in Group B half the subjects left the study resulting in 83 in the final sample. The number of patients per practice at the start of the study (mean = 7) had reduced by the final sample to an average of 4-5 patients in each practice.

Table 4. Mean number of subjects in each practice in the initial sample and final sample for Groups A and B

Baseline sample	Group A (n=150)	Group B (n=168)
Mean number of adults in each practice (range)	7.24 (1-28)	7.68 (2-22)
Final sample	Group A (n=107)	Group B (n=83)
Mean number of adults in each practice (range)	5.4 (1-25)	4.15 (1-18)

2.2.1 Reasons for drop out from the study

After baseline data were collected, the subjects in Group 1 received a health check and those in Group 2 had a second pre intervention data collection. During this second data collection, 25 adults withdrew from the study mainly due to unwillingness to give the time taken for the data collection (Table 5). For 7 of the adults, it was not possible to complete the data collection before the practice administered the health checks. The health checks were sent in the last weeks of data collection to give the practices maximum time to do them. As the practices were often unable to complete the health checks for several months, this procedure was usually successful. However, two practices were especially keen to do the health checks straight away and it was discovered that, on 7 occasions, the health checks had been completed before the data collectors had been able to visit the patient at home. Three adults died during the study, one between pre 1 and pre 2 data collection and 2 before the health check was conducted. Five adults moved practice and the research team was unable to contact them. Similarly, 6 moved house either from a family to a staffed home or between staffed homes. Due to having different staff support that would have occurred through moving residence, any changes in ability level or behaviour could be attributed to the move rather than the intervention and so these subjects were omitted from the study. Two practices withdrew from the study due to the pressures of workload, this removed a further 12 subjects.

Table 5. Reasons for drop out during study

		Group A	Group B	Total
Withdrawn before intervention	Withdrew during Pre 2 data collection	N/A	25	25
	Pre 2 data not collected in time	N/A	7	7
	Died during study	0	3	3
	Moved practice	0	5	5
	Moved house	1	5	6
	Practice withdrew from study	8	4	12
Did not receive a health check	Refused health check	0	2	2
	Health check not completed within time period	1	25	26
	Was not given health check	12	2	14
	Did not attend health check	7	3	10
Withdrawn after intervention	Withdrew during post data collection	7	5	12
	Data schedules mislaid	5	0	5
	Respondent changed	1	0	1
	Total number	**42**	**86**	**128**

In addition 52 adults did not receive a health check: 10 did not attend the health check appointment that was given to them; 26 did not receive a health check within the study period; 14 did not have a health check due to difficulties for the practice in contacting them, arranging a suitable appointment, or for reasons unknown and 2 refused the health check.

In the final data collection 12 adults withdrew from the study mainly due to time constraints or family illness and the data for schedules for 5 adults were mislaid due to a change in data collectors. On 1 occasion an individual living independently had answered all questions during baseline data collection, but a social worker had completed the questionnaires for the post data collection. This dataset was removed from the final analysis as changes on the measures could be attributed to the difference in respondent.

2.2.2 Initial and final samples by group

The initial and final samples were compared for any statistical differences in terms of the participants' age, level of ability (ABS), gender, residential status, presence of the triad of social impairment, presence of challenging behaviour (ABC) and indication of mental illness (PIMRA).

For the total sample there was no difference between the initial and final sample in terms of the mean age of the subjects participating or their ability level (Table 6). Similarly the subjects leaving the study did not affect the percentage of males and no differences were found between the initial and final samples with respect to the gender of participants. However, a higher percentage of participants were resident in staffed homes in the final sample, which was a significant change ($p<0.0001$) when compared to the initial sample. This would suggest that more participants from the family homes than the staffed homes left the study. For the presence of the triad of social impairment there was a difference between the initial and final sample at the significance level of $p<0.019$ indicating that more participants with the triad of social impairment had remained in the study compared to those without the triad. With respect to challenging behaviour and those with an indication of mental illness no statistical difference was found between the initial and final samples.

Table 6. Characteristics of subjects in the initial and final samples by group

	Total		Group A		Group B	
	Initial Sample (N=318)	Final Sample (N=190)	Initial Sample (N=150)	Final Sample (N=107)	Initial Sample (N=168)	Final Sample (N=83)
Mean age (range)	41.46 (17-86)	42.76 (17-86)	42.05 (17-86) ♦	43.38 (17-86	40.93 (17-77) ♦♦	41.95 (18-77)
Mean ABS score (range)	171.21 (14-304)	166.90 (31-304)	171.75 (25-301)	165.60 (31-290)	170.73 (14-304)	168.57 (35-304)
% Male	43.7	43.2	44.7	43.9	42.9	42.2
% Staffed home	45.6	53.7 ††	54.0	61.7 ++	35.7	43.4
% Presence of Triad	33.0	37.9 +	34.0	38.3	32.1	37.3
% With Challenging Behaviour	14.8	16.3	14.7	15.9	15.0	16.9
% With an indication of Mental Illness	45.9	43.4	40.9	40.6	50.3	47.0

♦ The final sample included 1 subject who was 17 at the time of baseline data collection but who received a health check as she had become 18 and therefore was included in the adult experimental group (group 1) for final data collection.

♦♦ Two subjects in the comparison group were also 18 by the time of the health check but were withdrawn, as they did not receive a second pre data collection.

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

The initial and final participants in Group A were not significantly different with respect to age, level of ability, gender, presence of triad, challenging behaviour and mental illness (Table 6). However, a significantly higher proportion of people were found to be resident in a staffed home in the Group A final sample when compared to the Group A initial sample

($p<0.007$), which indicated a higher number of people from the family homes leaving the study. The Group B initial sample and final sample were not found to differ significantly in terms of any of the measured characteristics of the participants.

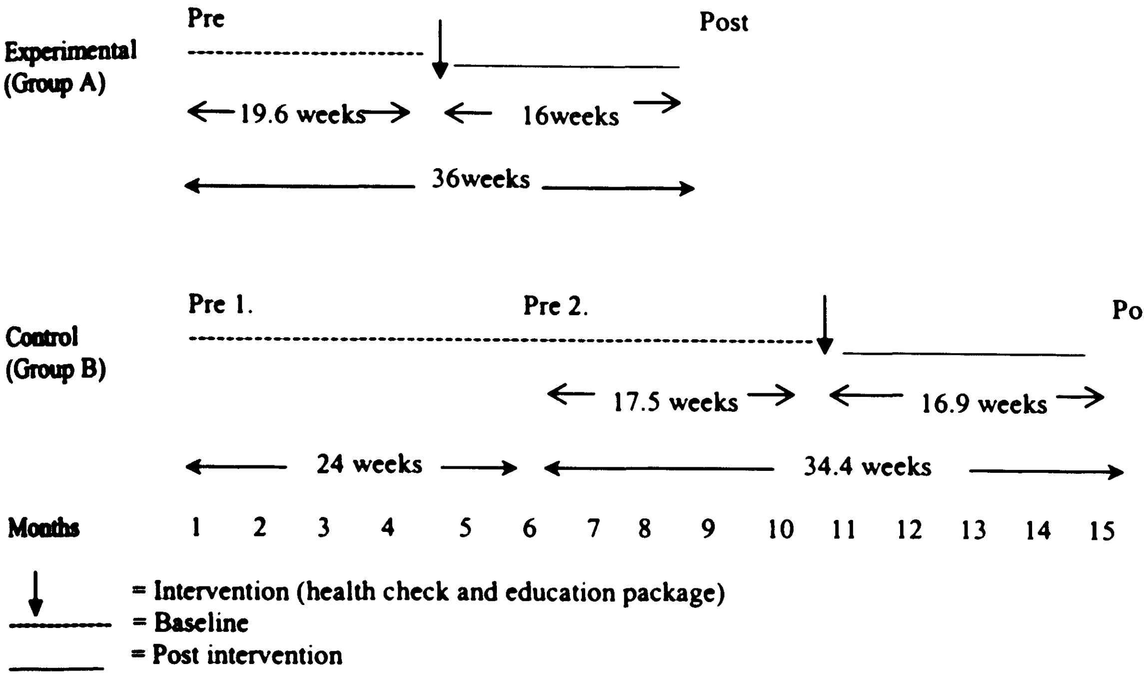
2.3 Study Design

2.3.1 Data collection

The study was designed to have a staggered process to data collection across the practices so that each period of data collection lead into the next. Baseline data were collected during a 12-month period from June 1999 to July 2000. A second data collection was conducted with the patients in the control group, which took place, on average, 24 weeks later (range 8 –37 weeks). The practices in the experimental group took a mean time of 19.6 weeks (range 3-48 weeks) and practices in the control group took 17.5 weeks (range 5-50 weeks) to administer the health checks (Figure 1).

The time period from the administration of the health checks till the final data collection was 16 weeks (range 6-50 weeks) for the experimental group and 16.9 weeks (range 4-38 weeks) for the control group. Thus the time period between the pre and post data collections was, for the experimental group 36 weeks (range 14-69 weeks), and for the control group 34.4 weeks (range 15-60 weeks). Originally all the data collections were planned to take place over the same period of time (i.e. 24 weeks), however, the practices generally took longer than anticipated to administer the health checks and, therefore, the overall time was nearer to 9 months during the period in which the health checks were conducted (Figure 1).

Fig 1. Study design



2.3.2. The intervention

The intervention consisted of a) chapters 2-9 of the Education Package (chapter 1 had been given to the primary care team previously to help in the identification of patients), b) the Cardiff Health Check and c) the Audit Interview.

a) The Education Package

Chapters 2-9 provided information on: Health Checking; Causation; Nutrition; Epilepsy; Challenging Behaviour; Autism; Sensory Impairment and Using Anti Psychotic Medication, and were sent with the health check forms to be used as a reference tool. The chapters were either written by doctors or academic specialists for the education pack or were drawn from previously published material on the particular topic. A brief synopsis of all nine chapters is given here:-

Chapter 1: Definition and Identification in the Practice

This chapter was aimed at enabling primary care team members to identify individuals with a learning disability on their practice register. The different terms used for learning disability were listed and the international classification to define someone who has a learning disability was given. A brief outline of some of the causes of learning disability including genetic, ante-natal, peri-natal and post-natal factors was given together with the level of impairment that would be expected for individuals with mild, moderate, severe and profound disability. A section was included on identification and prevalence to inform primary care team members of the numbers and percentage of individuals on the practice registers they could expect to identify.

Chapter 2: Health Checking

This chapter discussed evidence that barriers to health care exist for individuals with a learning disability which suggests the need for a more proactive approach. Recent research on the clinical effectiveness of health checks was also covered together with a short overview of different types of health checks that have been used for individuals with a learning disability. Also included was the 'Syndrome Specific Checklist', a chart designed as an easily accessible reference for health professionals of the main health concerns for seven of the more common learning disability syndromes (Down's syndrome, Prader-Willi, Fragile-X, Sturge Weber, Classical Phenylketonuria, Neurofibromatosis and Tuberose Sclerosis).

Chapter 3: Causation

This comprised extracts from a paper by Curry et al (1997) covering: the benefits of genetic evaluation; clinical evaluation, and diagnostic testing. The section on diagnostic testing included information on: Chromosome analysis, Fragile X analysis; Neuroimaging and Metabolic Testing. The aim of the chapter was to provide information on how to establish the causation of learning disability, as the Cardiff Health Check included a question on whether the cause of the patient's learning disability is known and if the results of a chromosome analysis are available. As specific syndromes carry with them associated health concerns, the importance of recognising if a patient has known syndrome is highlighted on the Health Check.

Chapter 4: Nutrition

The fourth chapter dealt with nutrition and comprised sections of a paper by Kennedy et al (1997), including a chart showing recommended actions for underweight individuals below a body mass index of 18, a section on individuals who are obese and also recommendations for health professionals outside the primary care team to be involved with nutritional support.

Chapter 5: Epilepsy

This included a description of each classification of epileptic seizure. The basic process of diagnosis of epilepsy was also covered together with the types of treatment available, including the main drugs used to control epilepsy, the side effects associated with each type of medication and the seizure type each should be used to treat. The monitoring of anti-epileptic medication, treatment of emergency situations and medication withdrawal were also addressed.

Chapter 6: Challenging Behaviour

The definition, prevalence and causation of challenging behaviour were outlined in this chapter, together with some of the more common identified functions of challenging behaviours. The assessment of individuals using functional analysis was highlighted and intervention strategies available to reduce the incidence and severity of challenging behaviour were also discussed.

Chapter 7: Autism

This chapter covered the identification, classification and aetiology of the autistic spectrum of conditions. Also included was an overview of the more common clinical features which may be present in someone with autism, along with a brief description of the psychological models currently used to explain these characteristics. Difficulties with diagnosis and common behaviour problems exhibited by individuals with autism were also discussed.

Chapter 9: Sensory Impairment

This was taken from a paper by Evenhuis et al (1997), which gave detailed information on the methods available for screening for sensory impairment in both children and adults with learning disabilities. The importance of early detection and treatment of sensory loss to prevent further unnecessary handicap was also highlighted.

Chapter 9: Using Anti-Psychotic Medication

The prevalence, the effectiveness in terms of modifying behaviour and the problems of anti-psychotic medication were covered in this chapter. Detail was also given on Tardive Dyskinesia, the most serious condition associated with prolonged use of anti-psychotic medication. Other side effects from the medication, difficulties with the reduction of anti-psychotics and the recommended guidelines for the reduction of medication were also discussed.

b) The Cardiff Health Check

The health check form followed a tick box format with 'yes' and 'no' answers in response to a series of questions on the individual's health covering the areas of: Health Promotion; Chronic Illness and Systems Enquiry; Epilepsy; Behaviour; Physical Examination; Syndrome Specific Check and Other Medication (see Table 7). The first section of the health check was completed by the research team and gave the name, address, sex, age, ethnic origin and principle carer of the individual. The health professional was required to enter the date at the top of the page and then complete the health promotion questions on the individual's: weight; height; blood pressure; urine analysis; body mass index and cholesterol. The health promotion section also included questions on indication for immunization (tetanus or influenza), whether Hepatitis B status was known and whether cervical screening and mammography had been performed. The next part of the health check enquired if the patient had any chronic illness, with particular reference to diabetes and asthma. This was followed by the systems enquiry which covered the presence of common symptoms in the following areas: respiratory; cardiovascular; abdominal; central nervous system; genitor-urinary and gynecological. The area of epilepsy was dealt with separately, with information required on the type, frequency and present status of epileptic seizures, a list of the current medication and on any side effects observed in the patient. Behavioural disturbance also had a distinct section on the health check and covered aggressive, self injurious, overactive or other behaviour and whether this occurred more than once a month, less than once a month or infrequently.

The physical examination followed after the behavioural section and comprised: general appearance; the cardiovascular system; respiratory system; abdomen; vision; hearing; communication; mobility; dermatology and breast examination. As with the other parts of the health check, responses to questions on each of these areas were given with a 'yes/no' tick box to indicate if any problems were found. At the end of the physical examination there was a general question on whether other investigations were necessary which gave the health professional the opportunity to note any areas not included previously. The final section, the 'Syndrome Specific Check', included: the cause of learning disability; whether chromosomal analysis had ever been conducted; the degree of learning disability; whether the patient's IQ had been tested and if a thyroid function test was indicated (i.e. if the individual had Down's Syndrome). Lastly, a grid was provided for the health professional to list all medication the individual was receiving, indicating the dosage, side effects and the levels of medication in the blood.

The health check was designed to take approximately 1 hour and the sections were ordered so that a practice nurse could complete the first half of the form and the doctor the remaining half, if this proved to be a more efficient way of conducting the health check. The practices were instructed to return all completed health check forms to the research team who made copies and returned the originals to the practice to be included in the patients' medical files.

c) The Audit Interview

The research team then visited the practice to conduct an audit interview with the primary care team member who had administered the health checks. The aim of the audit interview was to highlight any health needs identified during the health check and to discuss the resulting health actions. The average time interval between the health check and audit interview was 18 weeks with a range of 7 - 42 weeks. It was not possible to conduct an audit interview for nine of the 190 patients in the final sample, who had a complete data set and a health check conducted. For 5 patients, the doctor who had administered the health checks left the practice before the audits had been conducted and 4 audit interviews were not done by mistake, leaving 181 audits completed in total.

Table 7. Health areas included in the health check

Health Promotion		Chronic Illness and Systems Inquiry		The Physical Examination
Cervical screening		Endocrine		General appearance
Mammography		Respiratory		Respiratory system
Blood pressure test		Cardiovascular system		Cardiovascular System
Urine analysis		Abdominal System		Abdominal System
Weight		Central Nervous System		Central Nervous System
Height		Genito Urinary		Dermatology
Smoking rates		Gynaecological		Breast Examination
Cholesterol levels		Vision		Other Investigation
Alcohol consumption		Hearing		
Immunisation status		Communication		
		Mobility		

Epilepsy		Behaviour		Syndrome Specific Check
Blood levels		Aggression		Chromosomal Analysis
Medication Review		Self Injury		Thyroid Level check
Knowledge of seizure type		Over Activity		Other Investigations
Side effects considered		Other behaviour problems		

Other Medication
Medication review
Side effects considered

The audit interview involved ascertaining if checks had been performed on each of the seven areas of the health check: Health Promotion; Chronic Illness and Systems Enquiry; Physical Examination; Epilepsy; Behaviour; Syndrome Specific Check and Other Medication (Table 4). If the check had not been conducted then the reason was recorded in one of five categories: Refused by patient; Patient uncooperative; A clinical decision by the doctor or nurse; Refused by the carer or person accompanying and Other (e.g. problem with equipment). If the check was undertaken then the professional who undertook the check was recorded as: Doctor; Practice Nurse; Learning Disability Nurse or Other (e.g. community nurse).

The primary care team member who had conducted the health check was then asked if there had been a previous problem in this health area and what the planned course of action had been. The planned course of action was recorded under the following categories: Continue previous treatment; Change previous treatment; Introduce treatment; To be further investigated/monitored within the surgery; Referral to specialist; Liaise with other professional; No further action; Patient/carer refused intervention and Other. The health professional was then asked about the current status of the patient in terms of the course of action decided upon. The categories for these answers consisted of: Planned action taken and successful; Planned action taken and unsuccessful; Planned action in progress; Action not taken due to patient constraints; Action not taken due to practice constraints; Action not taken due to external agencies constraints and Change in planned action.

2.4 Measures

2.4.1 Selection of Measures

A number of researchers have emphasised the use of quality of life indicators to measure quality of outcome for both health provision and social services (Felce, 1996; Schalock et al., 2002). Indeed, the current view of quality of life as a multidimensional construct influenced by personal and environmental factors (e.g. relationships, housing, education and health) (Schalock et al., 2002), highlights the link between individuals' health and the quality of life they experience. In addition, many of the main life domains identified by quality of life researchers (productive well-being; material well-being; social well-being; emotional well-being and physical well-being) are currently measured within evaluation practice (Felce & Perry, 1997) and, therefore, the current study sought to apply well established measures to investigate the possible impact of the intervention on each of these quality of life domain areas for the individual.

Amongst other measures Felce & Perry (1997) recommended the use of the Adaptive Behavior Scale (Nihira et al., 1993) and measures of participation in ordinary living (i.e. Index of Community Involvement, Raynes et al., 1989) to assess the individual's productive well-being; the use of community involvement measures for social well-being and the use of general psychiatric screening instruments (e.g. Psychopathology Inventory for Mentally Retarded Adults, Matson, 1988) for emotional well-being. Accordingly, these measures were incorporated into the study as key quality of life indicators. In addition, it was considered appropriate to assess the presence of autism, challenging behaviour and perceived health of the individual, and therefore measures commonly used to assess these factors were also selected.

2.4.2 Patient Characteristics – Adults

Information was gathered on patients' level of ability, skills, maladaptive behaviour, mental health, quality of life, level of choice, epilepsy status and health status. Level of disability was measured using the Disability Assessment Schedule (DAS) (Holmes, Shah, & Wing, 1982), and skills on the Adaptive Behavior Scale Part 1 (ABS) (Nihira, Leland, & Lambert, 1993). Maladaptive behaviour was measured on the Aberrant Behavior Checklist (ABC) (Aman & Singh, 1986), and the Psychopathology Inventory for Mentally Retarded Adults (PIMRA) (Matson, 1988) was used to assess mental health status. Three quality of life indicators were measured: community involvement was measured using an amended version (Felce et al., 1998) of the Index of Community Involvement (ICI), (Raynes, Sumpton, &

Pettipher, 1989a), activity in the home was examined by use of the Index of Participation in Domestic Life (IPDL) (Raynes, Sumpton, & Pettipher, 1989b), and physical activity was measured using The Diary of Scheduled Activities (Lowe & Felce, 1994). In addition, the level of choice individuals were able to exercise within residential homes was measured using the Choice Questionnaire (Stancliffe & Parmenter, 1999), the Epilepsy Outcome Scale measured the level of carer concern for patients who had epilepsy (Espie et al., 1998), and the SF-36 (Ware, 1993) was used to measure perceived health status. Data were collected by interview primarily with direct carers: in family homes this was a parent, guardian or sibling and, for people living in residential homes, the person's keyworker was normally interviewed. Patients who were sufficiently able to act as respondents were asked to do so and this occurred in 10 cases only.

Test-retest reliability was conducted on: the Adaptive Behavior Scale, the Aberrant Behavior Checklist, the Psychopathology Inventory for Mentally Retarded Adults, the Index for Community Involvement, the Index for Participation in Domestic Tasks, and the SF-36. The same researcher re-administered the measure to the same respondent after an interval of 2 weeks, and reliability was calculated by totalling the number of agreement items, dividing this by the total number of items and multiplying by 100. The reliability conducted for this study, and the published reliability for each scale are both presented.

Disability Assessment Schedule (DAS) (Holmes et al., 1982)

The Quality of Social Interaction Scale (Wing & Gould, 1978) and the Triad of Social Impairments Scale (Wing & Gould, 1979) were used from the Disability Assessment Schedule. The Quality of Social Interaction Scale indicates if individuals are socially impaired in terms of how they respond to social contact from other people, and is used to identify the triad of social impairments associated with the spectrum of autism conditions. The triad of social impairments is constructed by combining the Quality of Social Interaction Scale with other items (lack of imaginative play or symbolic activities combined with a marked use of stereotypic or elaborate routines of behaviour, repetitive speech or echolalia) included in the DAS. The scale was administered by interview with the primary carer, at baseline only. Reliability between raters for the Quality of Social Interaction scale was reported by the authors to range between 77% (between parents and professional workers) and 94% (between the authors and professional workers) (Wing & Gould, 1978). Perry et al. (2000) found inter-respondent agreement on the presence/absence of the Triad of Social Impairment of 76%.

Adaptive Behavior Scale Part 1 2nd Edition (ABS) (Nihira et al., 1993)

The Adaptive Behavior Scale Part One is designed to assess individuals' ability to cope with their daily living environment. It consists of ten behaviour domains: Independent Functioning; Physical Development; Language Development; Numbers and Time; Economic Activity; Domestic Activity; Vocational/ Pre vocational Activity; Self-Direction and Responsibility and Socialisation. The scale is scored for each domain separately and totalled to give an overall scale score. Scores can also be converted into percentiles and age equivalent scores. The scale was administered by interview with the primary carer at baseline, pre 2 and post intervention. Test re-test reliability, conducted on 5% of the interviews found an average percentage agreement of 89% (range, 78-100%) The scale authors reported an average reliability of 94.8% with a range of 88-99% across each of the sub domains (Nihira et al., 1993).

Aberrant Behavior Checklist (ABC) (Aman & Singh, 1986)

The Aberrant Behavior Checklist was originally developed to measure behaviour changes achieved by medication treatment. It consists of 58 items divided into five subscales: Irritability (15 behaviours); Lethargy (16 behaviours); Stereotypy (7 behaviours); Hyperactivity (16 behaviours) and Inappropriate Speech (4 behaviours). Behaviours are rated according to severity, frequency of occurrence, degree of management problem and the effect on the individual's development. The primary carer completes the scale by rating behaviours on a four-point scale ranging from no problem (0) to severe problem (3). The scale yields a total score and a separate score for each domain. Following the published guidelines, the primary carer completed the scale, after a brief explanation from the researcher at baseline, pre and post intervention. Test re-test reliability conducted on the study found an average percentage agreement of 81% (range, 43-98), which was slightly lower than the reliability reported by the authors of an average of 98% (range, 96-99%) across each of the subscales (Aman & Singh, 1986).

The Psychopathology Inventory for Mentally Retarded Adults (PIMRA) (Matson, 1988)

The Psychopathology Inventory for Mentally Retarded Adults was designed for use as a diagnostic tool and is based on the major categories of the Diagnostic and Statistical Manual III (DSM-II) of the American Psychiatric Association. The scale can be used to assess seven types of psychopathology and is designed specifically for diagnosing conditions in people with learning disabilities under eight domains: Schizophrenia; Affective disorder; Psychosexual disorder; Adjustment disorder; Anxiety disorder; Somatoform disorder; Personality disorder, and Inappropriate adjustment. This scale can also be used for research purposes to assess change in mental health and to establish the prevalence of psychopathology in people with learning disabilities. The PIMRA consists of two structured interviews: the first conducted with a primary carer or supervisor and the second with the individual with a learning disability. Only the first interview was conducted in this study, as the second interview relies on a degree of clinical judgement by a mental health professional. The scale was administered by interview with the primary carer at baseline, pre and post intervention. Test-retest reliability on 5% of interviews conducted with the sample yielded an average percentage agreement of 88% (range, 75-98), which was similar to the average reliability of 91% reported by the scale author (Matson, 1988).

The Choice Questionnaire (Stancliffe & Parmenter, 1999)

This questionnaire is designed to measure the degree of choice exercised by the individual. It contains 26 items which are divided into six domains of: domestic activity, staff and the other people you live with; money and spending; health; social activities, community access and personal relationships; work/day activities and overall choice. The measure concentrates on objective measures of choice (e.g. do you have your own key to the house?) rather than a subjective opinion (e.g. the extent of an individual's satisfaction about the amount of choice they have). The scale is scored by summing the total for each domain and for the scale overall. The individual with learning disabilities or the main carer can complete the scale. It contains two additional items designed to test for a recency effect in the memory of the individual with learning disabilities: should these items show any response bias, the rest of the questions are not asked. The authors suggest that self-completions and proxy completions of the scale do not yield interchangeable data, as the level of agreement between staff and users is not high and may be reflecting different viewpoints. For the purposes of this study the scale was administered at baseline, pre 2 and post intervention, by interview with the primary carer only as the scale was not used with individuals themselves. No reliability testing was conducted during the study, but the authors reported an average level of test-retest reliability of 97% for staff report (Stancliffe & Parmenter, 1999).

The Index of Community Involvement (ICI) (Raynes et al., 1989a)

The Index of Community Involvement is designed to measure the social activities and community involvement of the individual. It consists of 15 items, 14 of which related to whether the person has used specific facilities in the past month, and one that asks if the person has been on holiday in the past year. An adapted version of the original scale was used (Felce et al, 1998), to ascertain also the frequency with which facilities had been used. In the original scale, a score of one was given for each facility used, resulting in a total possible score of 16. In the amended version, the number of times the person had used the facility in the past month was also recorded up to a maximum number of 5, resulting in a possible total score of 80. The scale was administered by interview with the primary carer. Test-retest reliability was conducted on 5% of the interviews conducted, and this achieved an average agreement of 81% (range, 38-100). The authors, however, presented only inter-rater reliability, which achieved a level of agreement of 92% (Raynes et al., 1989a).

The Index of Participation in Domestic Life (IPDL) (Raynes et al., 1989b)

The Index of Participation in Domestic Life assesses the degree to which individuals are involved in the domestic tasks around their home. The scale comprises 13 items, on tasks such as shopping for food, doing the ironing and gardening. It gives a score of nil if the task is not undertaken, one for each task undertaken with help from a carer, and two for any task undertaken without help, thus allowing a possible total score of 26. The scale was administered by interview with the primary carer at baseline, pre 2 and post intervention. Test-retest reliability was conducted on 5% of the interviews conducted with an average agreement of 81% (range, 31-100). The scale authors reported inter-rater reliability, with a range of 95-97% agreement (Raynes et al., 1989b).

Diary of Scheduled Activities (Lowe & Felce, 1994).

The Diary of Scheduled Activities was designed to gain information on the pattern and duration of planned activities over a typical week. It consists of a seven-day account of the individual's regular scheduled activities, which are recorded in half-hour slots from 9:00am till midnight. It was adapted slightly for this study, in that additional information was gained on the degree of physical activity involved: a note was made as to whether the activity was physically active (e.g. housework, walking and gardening), physically energetic (e.g. swimming and aerobics) or passive (e.g. aromatherapy and sensory room sessions). The scale was scored by calculating the amount of time scheduled during the week for physical and energetic activity. The scale was completed by interview with the primary carer at baseline, pre and post intervention, who was asked to refer to records where applicable. Reliability data were not collected for this measure.

The Epilepsy Outcome Scale (Espie et al., 1998)

The Epilepsy Outcome Scale was developed from The Epilepsy Knowledge Questionnaire (Jarvie, Espie, & Brodie, 1993) and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) to form a scale of 40 items representing concerns about epilepsy. Four subscales of concern about epilepsy (concerns about seizures, drugs, injury and daily life) are rated on a Likert scale of 0 to 4, with a score of 4 representing the highest level of concern. The primary carers of all subjects who were known to have epilepsy completed the scale at baseline, pre 2 and post intervention. The authors reported test-retest reliability of 0.85, for the total score with a range of 0.68 to 0.86 reported across the subscales (Espie et al., 1998).

The SF-36 (Ware, 1993)

The SF-36 is a general health questionnaire designed for measuring the perceived health status in the general population. A proxy version of the scale was used which was specifically designed for use with people with communication difficulties and is completed by the primary carer. It comprises 36 questions covering eight subscales (Physical Functioning; Role Physical; Bodily Pain; General Health; Vitality; Social Functioning; Role Emotional and Mental Health) and an additional item (Reported Health Transition), which is treated individually. The scale was scored by calculating a total for each of the subscales and a separate individual score for the transitional item. The primary carer completed the scale, after a brief explanation from the researcher at baseline, pre 2 and post intervention. Test-retest reliability was conducted on 5% on of the interviews with a percentage agreement of 69% (range, 44-94%). The authors report a study by Brazier, et al., (1992), conducted in the UK that obtained test-retest reliability with a median of 76% (range, 60-81%) for the standardised version, rather than the proxy version of the scale.

2.4.3 Carer stress and health measures

Carer stress was assessed by the Malaise Inventory (Rutter et al., 1970a; 1970b) and the Caregiver Strain Index (Robinson, 1983) for family members caring for the patient at home, and by the Maslach Burnout Inventory (Maslach & Jackson, 1981) for paid carers in staffed houses. The health status of all carers was assessed using the SF-36 (Ware, 1993) at baseline, pre 2 and post intervention. Test re-test reliability was conducted on the SF-36 only and was assessed by the same researcher administering the measure to the same respondent after an interval of 2 weeks. Reliability was calculated by totalling the number of agreement items, dividing this by the total number of items and multiplying by 100. The published reliability from the authors of each of the scales is also presented.

The Malaise Inventory (Rutter et al., 1970a; 1970b)

The Malaise Inventory was used to measure the stress levels of primary carers and spouses. The scale assesses both physical and psychological malaise, using 24 items. Each respondent is asked to read a list of statements, and answer whether the statement is true for themselves or true for their spouse. The scale gives a score of one for each answer of yes, giving a possible total score of 24 for each primary carer and spouse. For the purposes of analysis in the current study these scores were averaged to give one overall score for each carer couple, or, where there was no spouse, only the score from the primary carer was used. The main carer completed the scale, after a brief explanation from the researcher at baseline, pre 2 and post intervention. The scale authors reported an average test re-test reliability of 91% agreement (Rutter et al., 1970b).

Caregiver Strain Index (Robinson, 1983)

Originally developed for use with non-professional carers of the elderly (e.g. family members, neighbours, spouses), the scale has been used to assess other informal systems of care such as family carers of people with learning disabilities. The word "strain" was omitted from the title on the questionnaire as personal experience indicated that this might affect the openness of response from family carers, who may be sensitive to the suggestion that they found the care of their child a strain. The scale is designed to assess the level of strain the primary carer experiences in caring for the individual. The scale consists of 13 items and is scored by giving a score of one for each answer of yes, giving a possible total score of 13. The primary carer completed the scale, after a brief explanation from the researcher, at baseline, pre 2 and post intervention. The author, using Cronbach's alpha, reported internal reliability at a level of 0.86 for the scale (Robinson, 1983).

Maslach Burnout Inventory (Maslach & Jackson, 1981)

This scale measures three aspects of "burnout" (a syndrome of emotional exhaustion and cynicism) using three sub-scales: Emotional Exhaustion; Depersonalisation and Lack of Personal Accomplishment. The scale consists of twenty-two statements that carers are asked to rate how often they feel that way (frequency) and how strongly (intensity). For each staffed home, three members of staff were selected at random and asked to complete the scale and return it to the research team. Any references to "burnout" were omitted from the scale, as suggested by the authors, and all responses were kept anonymous. This scale was only administered in staffed homes, as it was unsuitable for use in family homes. As all staff members were often not present at the time the researcher visited the home, three copies of the scale were left for respondents to complete and return in stamped, addressed envelopes at baseline, pre 2 and post intervention. The authors reported test-retest reliability coefficients of 0.82 (frequency) and 0.53 (intensity) for Emotional Exhaustion, 0.60 (frequency) and 0.69 (intensity) for Depersonalization and 0.80 (frequency) and 0.68 (intensity) for Personal Accomplishment (Maslach & Jackson, 1981).

SF-36 (Ware, 1993)

The SF-36 was used again with the main carer as a measure of their own general health status. The SF-36 for the carer was not used in the homes of subjects who lived independently which occurred in 10 cases. The standardised version, which was designed for use in the general population, was used. The scale comprises the same 36 questions as in the proxy version described earlier, and is scored in exactly the same way. The primary carer completed the scale, after a brief explanation from the researcher, at baseline, pre 2 and post intervention. Test-retest reliability was assessed and a percentage agreement of 75% (range, 44-97%) was obtained, which is similar to the median level of reliability of 76% (range, 60-81%) obtained by Brazier, et al (1992).

2.4.4 Setting Characteristics

For staffed homes, information on the type of home, number of residents and staff qualifications was collected. The Working Methods Scales (Lowe, Felce, Perry, Baxter, & Jones, 1998) was used to record staff training and operational processes in the home. This information was collected from a senior member or manager of each residential home. These measures were inappropriate for use in family homes.

Working Methods Scale (Revised) (Lowe et al., 1998)

The Working Methods Scale relates to the practices and methods used in the home for supporting clients. It consists of 5 sections: individual planning; assessment and teaching; planning daily/weekly activities; staff support of resident activity and staff training and supervision. The section on the training, qualifications and management of the staff was used for the purposes of this study.

2.5 Analysis

The data for each of the 36 variables were firstly examined by using the Statistical Package for the Social Sciences (version 11) to plot a normal curve on a histogram and a Q-Q plot to determine whether the scores were normally distributed. This was done separately for the experimental and control groups and for each of the sub groups. For only 4 of the variables was there substantial evidence of a Normal distribution and so it was decided to use the more conservative non parametric tests in analysis, rather than their parametric equivalents. For clarity therefore the Mann Whitney U test (two tailed) was used to test between-group differences, and the Wilcoxon Matched-Pairs Signed Ranks test (two tailed) was used to test within-group changes, across all measures. Details of the statistical tests used can be found in Siegel (1956).

As a number of repeated tests were being performed the Bonferroni test was applied to correct for the likelihood of obtaining a type 1 error. Consideration was also given to the use of multivariate approaches and advice was sought from a statistician. Transformations were considered, particularly taking logarithms. Residuals factor model fitting were tested for normality but again the majority of the variables were not Normally distributed. There are also problems in interpreting the results for transformed data as they are on different scales from the original. Accordingly it was felt that the use of multivariate methods was not especially appropriate.

3.0 Results

3.1 Presentation of Results

The primary aim of this study was to assess a total population of people with learning disabilities before and after the routine administration of health checks to investigate any impact on their quality of life and that of their carers. In accordance with this, the results presented first relate to the full samples observed, analysed separately according to residential setting. The results were then re-analysed to investigate whether individuals' characteristics, in terms of the presence or absence of social impairment, the presence or absence of challenging behaviour and the presence or absence of mental health problems, could be identified as possible factors in any differential impact observed. A further re-analysis was then conducted to examine any differential impact according to whether or not the health needs were identified, and whether or not they were subsequently treated during the course of the study period.

Prior to the presentation of the results on the impact of the health checks, an analysis of the actual health checks conducted as part of the study is given, to describe the nature and scope of the health needs identified.

3.2 The Health Needs Identified During the Health Check

Of the 190 subjects who had the health check, 181 individuals had the audit interview performed. It was not possible to conduct the audit for the remaining 9 subjects; in 5 cases the health professional who had conducted the health check had left the surgery and 4 audits were omitted by mistake. Ninety-three (51%) of the 181 individuals had one or more health needs identified: 58 (62%) in Group A and 35 (38%) in Group B; representing 57% and 44% of the groups respectively and, across these a collective 148 previously unidentified health needs were found (Table 8). Forty-four subjects in each group had no health needs identified, representing 43% and 56% of Groups A and B, respectively. The two residence types were evenly represented across the total sample, with 51% of them in family homes and 50% in staffed homes having a health need identified. Slightly different patterns were evident in the two samples, with 62% in family homes and 56% in staffed homes in Group A having a health need identified, compared to 40% and 48%, respectively in Group B.

Table 8. Health needs identified by group and residence

	Group A			Group B			Total		
	Total Sample	Family Homes	Staffed Homes	Total Sample	Family Homes	Staffed Homes	Total Sample	Family Homes	Staffed Homes
Health needs identified	58 (57%)	20 (62%)	35 (56%)	35 (44%)	16 (40%)	16 (48%)	93 (51%)	36 (50%)	51 (53%)
No health needs identified	44 (43%)	12 (38%)	28 (44%)	44 (56%)	24 (60%)	17 (52%)	88 (49%)	36 (50%)	45 (57%)
Total	102 (100%)	32 (100%)	63 (100%)	79 (100%)	40 (100%)	33 (100%)	181 (100%)	72 (100%)	96 (100%)

A slightly higher number of health needs were identified for those in Group A, with an average of 1.6 health needs found per person compared with an average of 1 health need per person in Group B. However, the distribution of health needs identified across the 4 health check areas were similar in each group (Table 9). The highest percentage of the health needs were found in the area of sensory impairment (38.5%), which accounted for nearly half of the health needs identified for Group B (49%) and a third of the health needs identified for subjects in Group A (33%). Health promotion indicators accounted for a third of the health needs identified for those in Group A (33%), a fifth for those in Group B (21%) and 29% across the total group. Other health needs were identified at a similar level in both groups: 19% of the health needs in Group A and 14% in Group B. A similar level of health needs in both groups was identified from the systems enquiry and physical examination (Group A = 15%, Group B 16%). Eight of the 148 health needs identified were classified as serious conditions by a learning disability psychiatrist qualified in general practice and these are highlighted in grey in Tables 10, 11, and 13.

Table 9. The percentage of health needs identified in each group by health check area

Health Check Area	Group A N=58	Group B N=35	Total N=93
Health promotion indicators	32 (33%)	11 (21%)	43 (29%)
Other health needs identified	18 (19%)	7 (14%)	25 (17%)
Sensory impairment identified	32 (33%)	25 (49%)	57 (38.5%)
Health needs identified from systems enquiry and physical examination	15 (15%)	8 (16%)	23 (15.5%)
Total	97 (100%)	51 (100%)	148 (100%)

3.1.1 Health promotion

On completion of the health promotion section (weight, height, urine, cholesterol, and immunisations), additional tests or advice were sometimes indicated. These were recorded as health indicators and included as previously unidentified health needs. For example, if the individual had a high body mass index, dietary advice may be given or, if blood or glucose was identified in the urine, then further tests would be necessary to examine the cause. Only in these instances, that is, when the health promotion lead to further tests or some form of further action, was this recorded as a health need.

Of the 43 health promotion indicators found, just over half were for thyroid function tests (a recommendation for all individuals who have Down's Syndrome) and, from these tests, two cases of hypothyroid were identified (Table 10). Weight problems accounted for 12% of the health needs, and blood or glucose was found in the urine for 18% of cases. Two of the instances of glucose identified lead to a positive diagnoses of diabetes, which was classified as a serious condition. Four cases of high blood pressure were identified, together with 3 instances of high levels of cholesterol (7%). The only case of attendance for a mammography resulted in a subsequent diagnosis of breast cancer.

Table 10. Health indicators and confirmed illness identified as a result of health promotion actions conducted at the health check

Health need identified	**Total**
Overweight	5 (12%)
High blood pressure	4 (9%)
Blood found in urine (Haematuria)	4 (9%)
Glucose found in urine **(Confirmed as diabetes)**	4 (9%) **(2)**
High Cholesterol	3 (7%)
Thyroid function test indicated (Down's Syndrome) **(Confirmed as hypothyroid)**	22 (52%) **(2)**
Mammography indicated **(Confirmed as cancer)**	1 (2%) **(1)**
Total number of indicators from health promotion	**43 (100%)**

3.1.2 Behavioural and other problems

In total, 25 health needs were identified from the sections of the health check concerning behavioural and other problems (Table 11), including one serious health need of suspected dementia. Just over half (52%) of the needs identified were for skin conditions, while mobility problems accounted for a further fifth. Other health actions indicated were to do with medication, with two instances each of medication change and the need to check blood levels for anti-epileptic medication. One instance of behaviour problems was identified and one case of dental problems was also found.

Table 11. Behavioural and other problems identified

Health Need Identified	**Total**
Suspected dementia	**1 (4%)**
Behaviour problem	1 (4%)
Mobility problem	5 (20%)
Skin problem	13 (52%)
Dental problem	1 (4%)
Medication change necessary	2 (8%)
Medication blood levels to be monitored	2 (8%)
Total number of medical problems identified	**25 (100%)**

3.1.3 Sensory impairment

The largest proportion of previously unidentified health needs was found in the area of sensory impairment (38.5%), although none was considered serious (Table 9). The vast majority (81%) concerned the presence of blocked ear wax (Table 12), and this represented 31% of the total health needs identified across all the health check areas. Seven cases of difficulties with vision were found, while two individuals were found to have hearing problems. One case of a previously undiagnosed eye infection was found and another was of an infection of the ear canal, collectively accounting for 4% of the health needs identified in this section.

Table 12. Sensory impairment diagnosed at the health check

Health Need Identified	Total
Vision difficulties	7 (12%)
Eye infection	1 (2%)
Hearing difficulties	2 (3%)
Blocked ear wax	46 (81%)
Ear canal inflamed (otitis externa)	1 (2%)
Total number of new cases of sensory impairment	**57 (100%)**

3.1.4 Health needs identified at systems enquiry and physical examination

Table 13 shows the health check areas of the systems enquiry and physical examination where health needs were identified, in the areas of the Central Nervous System and General Appearance no health needs were identified. Two serious health needs were identified systems enquiry and physical examination: one case of asthma and one for the necessity of cardiovascular monitoring. The greatest proportion of health needs identified in this area concerned digestion (35%), including conditions of dyspepsia, weight loss, constipation, diarrhoea, flatulence and haemorrhoids. Genito-urinary problems was the next most prevalent area with 7 cases (30%) comprising: 4 instances of urinary tract infection; 2 of incontinence and 1 of painful urination. Three cases were identified in the area of the lungs, including the serious condition of asthma, one case breathing difficulties and one of unusual lung sounds. The heart problems were identified for 3 cases with one instance of cardiovascular monitoring and 2 of systolic murmur. Two cases of gynaecological problems were found, which were post menstrual bleeding and painful menstruation.

Table 13. Health needs identified at systems enquiry and physical examination

Health Need Identified			**Total**
Problems with lungs	3 (13%)	**Asthma**	**1**
		Difficulty breathing (dyspnoea)	1
		Unusual lung sounds	1
Problems with heart	3 (13%)	**Cardiovascular monitoring necessary**	**1**
		Systolic murmur	2
Problems with digestion	8 (35%)	Disordered digestion (dyspepsia)	1
		Weight loss	1
		Constipation	3
		Diarrhoea	1
		Flatulence	1
		Haemorrhoid	1
Problems with genito-urinary	7 (30%)	Painful urination (Dysuria)	1
		Incontinence	2
		Urinary tract infection	4
Gynaecological	2 (9%)	Post menstrual bleeding	1
		Painful menstruation (Dysmenorrhoea)	1
Total number of health needs identified	**23 (100%)**	**Total number of health needs identified**	**23**

In summary of the 148 health needs identified during the health check process, 8 (5%) of these were classified as serious conditions: two cases of hypothyroidism; two cases of diabetes; one case of suspected dementia; one case of cardiovascular problems; one case of asthma and one of breast cancer. The largest number of health needs was identified in the area of sensory impairment, which covered two fifths of the total number of health needs identified.

In the total sample a similar proportion of individuals were identified to have one or more health needs identified in both the family and staffed homes (51% and 50%, respectively). Across the two groups, a slightly higher proportion of individuals were found to have a health need identified in Group A (FH = 62% and SH = 56%) compared to Group B (FH = 40% and SH = 48%).

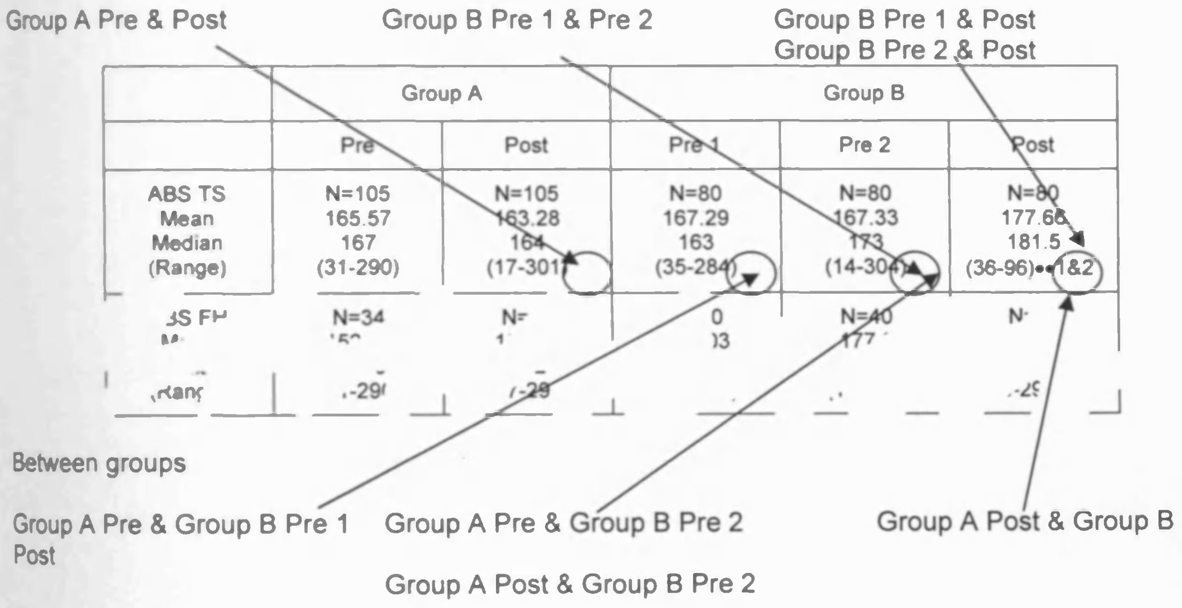
Notes on how to view tables

Within group change
For Group A the significance levels for within group changes are indicated in the 'Post' column. For Group B, the significance levels for changes between Pre 1 and Pre 2 are indicated in the column for Pre 2. The symbols used in the Post column are followed by a 1 or a 2 written after the symbols to indicate whether the within group difference was between Pre 1 or Pre 2 and the Post scores.

Between group change
The significance levels for between group differences are shown in the columns for Group B. A significant difference between Group A Pre and Group B Pre 1 is indicated in Group B Pre 1 column. And a significant difference between Group A Post and Group B Post is shown in the Group B Post column. Any significant difference between Group A Pre and Group B Pre 2 and between Group A Post and Group B Pre 2 is shown in the Group B Pre 2 column with the words "Pre" or "Post" written after the symbols to indicate whether the difference was with the pre or the post scores of Group A (see diagram below).

Where significant differences will be indicated on the tables

Within groups



	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS TS Mean Median (Range)	N=105 165.57 167 (31-290)	N=105 163.28 164 (17-301)	N=80 167.29 163 (35-284)	N=80 167.33 173 (14-304)	N=80 177.68 181.5 (36-96)••1&2

Adjustment for multiple comparisons - The Bonferroni Test (Miller, 1977)

As a large number of measures were used the likelihood of obtaining a type 1 error was quite high. To correct for this, the Bonferroni test was applied which controls for the error rate by dividing the experimental error rate ($p<0.05$) by the number of tests used, which, in this case, was 288. Thus the significance level used to correct for multiple comparisons was $p<0.00017$. The statistical tests that reached this significance level are discussed separately at the end of each section.

Notes on how to view tables

	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS TS Mean Std Deviation (Ra	N=105 165.57 67.37 (31-290)	N=105 163.28 68.37 (17-301)	N=80 167.29 63.62 (35-284)	N=80 167.33 62.19 (14-304)	N=80 177.66 65.06 (36-296)••1&2
SH viation (Range)	5 (45-279)	5 (44 2)	N 3 (45-	N (38-	27 •2
PIMRA TS Mean Median (Range)	N=106 10.49 10 (1-30)	N=106 9.57 9 (0-36) *	N=80 11.55 11 (0-30)	N=80 10.19 9 (0-33) **	N=80 9.78 9 (1-25) *1
H (nge)	(1-2	3 (3-2	N=41 0)	N=4 (1-33	N 3)
PIMRA SH Mean Median (Range)	N=66 11.15 11 (1-30)	N=66 9.56 9 (0-36) *	N=36 13.69 12 (4-29) +	N=36 12.91 13 (0-32) + Post	N=36 12.08 13 (2-25) +

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

TS = Total Sample **FH = Family Homes** **SH = Staffed Homes**

Example 1 (arrow at the top of the diagram)

The •• 1&2 next to the range indicates that the mean score was found to differ from both the scores at Pre 1 and at Pre 2 at p<0.001. The cell below where the arrow is pointing, shows a *1 which indicates a difference in the scores between Pre 1 and Post at the significance level of p<0.05.

Example 2 (arrow in the middle of the diagram)

The ** indicates a within group change between the Pre 1 and Pre 2 scores for Group B at p<0.01.

Example 3 (arrow at the bottom of the diagram

The +Post next to the range indicates that there was a between group difference between Group A Post and Group B Pre 2 at p<0.05.

3.3 The Total Sample, Family and Staffed Homes

3.3.1 Adaptive Behavior Scale (ABS)

Subject's ability levels were measured on the ABS (Table 8). The total scores for both groups were compared at baseline and, although Group A (median = 167) presented a slightly higher skills level than Group B (median = 163) no significant differences were detected between them. Group A showed a slight decrease in score over time (Pre = 167, Post = 164), but this did not achieve statistical significance. Group B remained stable between Pre 1 and Pre 2, with a slight, non-significant increase in overall score from 163 to 173.5. However, the scores in Group B increased at Post (median = 181.5) and significant differences were detected between Pre 1 and Post and between Pre 2 and Post; both at $p<0.0001$, which was beyond the significance level indicated by the Bonferroni Test ($p<0.00017$). However, at no time point did the differences between the groups reach statistical significance.

The family home participants in Group B showed a higher level of ability at the outset (median = 168) than those in Group A (median = 157.5) but this was not statistically significantly. Over time, no significant change occurred for those in Group A, while those in Group B showed a non-significant increase between Pre 1 (168) and Pre 2 (180), with a further slight increase at Post (181.5). This resulted in a significant change between Pre 1 and Post at the level of $p<0.003$. As no significant change was detected between Pre 2 and Post, however, this may indicate an increasing trend in scores over time, rather than any intervention effect. Moreover, no statistically significant differences were detected between the groups at any time point, with respect to the family home participants.

In contrast to the total sample and the family homes, a higher level of ability was found for Group A with respect to the staffed home participants (median = 165) compared to those in Group B (median = 158). The scores for those in Group A showed a small, non-significant decrease with a similar pattern evident for those in Group B, indicating stability in the scores. The scores for those in Group B increased at Post representing a significant change between Pre 1 and Post ($p<0.005$) and between Pre 2 and Post ($p<0.002$). There were no significant differences detected between the groups for the staffed home participants at any time.

3.3.2 Psychopathology Instrument for Mentally Retarded Adults (PIMRA)

The PIMRA was used to measure the level of mental illness (Table 8). Similar scores were obtained at baseline, for Group A (median = 10) and Group B (median = 11) with no significant difference found between them. Although the scores in Group A showed only a slight overall decrease, this did reach significance at $p<0.035$. In Group B too, a small but significant decrease was detected between Pre 1 and Pre 2 ($p<0.008$), indicating the scores to be unstable over time. A significant change was also found between Pre 1 and Post ($p<0.005$), but not between Pre 2 and Post. At no time point were the differences between the two groups found to be statistically significant.

In both groups, the family home participants' scores indicated a generally lower level of mental illness (median = 8 for both). Little change was noted and no significant between group differences or within group changes occurred.

Table 14. Adaptive Behavior Scale (ABS) and Psychopathology Instrument for Mentally Retarded Adults (PIMRA)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS TS	N=105	N=105	N=80	N=80	N=80
Mean	165.57	163.28	167.29	167.33	177.66
Median	167	164	163	173.5	181.5
(Range)	(31-290)	(17-301)	(35-284)	(14-304)	(36-296) ••1&2
ABS FH	N=34	N=34	N=40	N=40	N=40
Mean	152.29	153.53	176.03	177.0	182.9
Median	157.5	162	168	180	181.5
(Range)	(31-290)	(17-295)	(35-278)	(14-266)	(36-296) •1
ABS SH	N=64	N=64	N=35	N=35	N=35
Mean	163.50	158.38	144.42	142.86	158.20
Median	165	161	158	153	172
(Range)	(45-279)	(44-282)	(45-243)	(38-224)	(36-270) •1 •2
PIMRA TS	N=106	N=106	N=80	N=80	N=80
Mean	10.49	9.57	11.55	10.19	9.78
Median	10	9	11	9	9
(Range)	(1-30)	(0-36) *	(0-30)	(0-33) **	(1-25) **1
PIMRA FH	N=33	N=33	N=41	N=41	N=41
Mean	8.82	8.82	9.76	8.37	8.27
Median	8	7	8	7	8
(Range)	(1-23)	(3-27)	(0-30)	(1-33)	(1-23)
PIMRA SH	N=66	N=66	N=36	N=36	N=36
Mean	11.15	9.56	13.69	12.91	12.08
Median	11	9	12	13	13
(Range)	(1-30)	(0-36) *	(4-29) +	(0-32) +	(2-25) *1 +

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Higher levels of mental illness were found for those in the staffed homes when compared to those in the family homes (medians 11 and 12 respectively). A statistically significant difference was found between the participants of the two groups at the outset, which suggested higher levels of mental illness for those in Group B (p<0.026). A slight decrease in score was detected in Group A that reached the significance level of p<0.012. Some fluctuation in the scores for those in Group B was evident, however, it was not possible to compare the two groups any further, due to the difference in scores at baseline.

3.3.3 Aberrant Behavior Checklist (ABC)

Total Score (Tot)

As can be seen in Table 9 similar ABC total scores were obtained at baseline for both groups (medians 14 and 15.5, respectively). Although the overall level of reported behaviour disorders decreased slightly over time for Group A, this did not achieve statistical significance. The median score for Group B increased to 18 at Pre 2 and back down to 13 at Post, resulting in a significant improvement compared to Pre 2 ($p<0.046$); but not Pre 1. At no time point did any differences between the groups achieve statistical significance.

The family home participants showed generally lower levels of behaviour disorder at baseline with medians of 12 and 8.5 respectively. For those in Group A no significant change occurred, although the median decreased to 9. In Group B the median decreased to 6.5 at Pre 2 and then rose slightly to 7 at Post which resulted in a significant change between Pre 1 and Post at $p<0.05$ but not between Pre 2 and Post. Again at no time point did the two family home groups differ significantly.

Table 15. Aberrant Behavior Checklist (ABC)

Total Sample (TS) **Family Homes (FH)** **Staffed Homes (SH)**	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABC Tot TS **Mean** **Median** **(Range)**	N=104 22.59 14 (0-87)	N=104 21.66 10 (0-104)	N=80 23.76 15.5 (0-115)	N=80 24.18 18 (0-92)	N=80 19.94 13 (0-94) *2
ABC Tot FH **Mean** **Median** **(Range)**	N=34 18.91 12 (0-77)	N=34 18.15 9 (0-104)	N=40 17.45 8.5 (0-115)	N=40 15.38 6.5 (0-83)	N=40 12.88 7 (0-73) *1
ABC Tot SH **Mean** **Median** **(Range)**	N=63 25.79 17 (0-87)	N=63 24.27 16 (0-83)	N=36 32.58 23.5 (5-88)	N=36 36.17 34.5 (7-92) †Pre ††Post	N=36 29.25 24.5 (4-94) *2
ABC TN TS **Mean** **Median** **(Range)**	N=104 14.52 12 (0-46)	N=104 14.35 10 (0-49)	N=80 15.74 13 (0-51)	N=80 16.71 15.5 (0-52)	N=80 14.45 11 (0-46) *2
ABC TN FH **Mean** **Median** **(Range)**	N=34 12.94 11 (0-36)	N=34 13.24 8.5 (0-47)	N=40 11.70 8.5 (0-51)	N=40 10.83 5.5 (0-49)	N=40 9.35 6 (0-36) *1
ABC TN SH **Mean** **Median** **(Range)**	N=63 16.10 12 (0-46)	N=63 15.55 11 (0-49)	N=36 21.36 19.5 (5-44) +	N=36 24.67 24 (6-52) ††Pre ††Post	N=36 21.08 18.5 (4-46) +
ABC T3s TS **Mean** **Median** **(Range)**	N=104 2.10 0 (0-18)	N=104 1.67 0 (0-20)	N=80 2.06 0 (0-24)	N=80 1.46 0 (0-13)	N=80 1.25 0 (0-15)
ABC T3s FH **Mean** **Median** **(Range)**	N=34 1.47 0 (0-16)	N=34 1.24 0 (0-20)	N=40 1.68 0 (0-24)	N=40 1.25 0 (0-13)	N=40 0.83 0 (0-15)
ABC T3s SH **Mean** **Median** **(Range)**	N=63 2.57 0 (0-18)	N=63 1.84 0 (0-15)	N=36 2.67 0 (0-20)	N=36 1.86 0.5 (0-11)	N=36 1.86 0 (0-15)

* **Significant within group change at p<0.05**
** **Significant within group change at p<0.01**
• **Significant within group change at p<0.005**
•• **Significant within group change at p<0.001**

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

The staffed home participants, in particular those in Group B, showed higher levels of behaviour problems at the outset (medians 17 and 23.5, respectively). Although Group B participants showed higher scores than those in Group A this was not statistically significant. Little change was detected for those in Group A and no significant changes were found. Participants' scores in Group B rose between Pre 1 and Pre 2, which resulted in a significant between group difference between Group A Pre and Group B Pre 2 (p<0.003) and between Group A Post and Group B Pre 2 (p<0.001). The scores for those in Group B dropped back down at Post resulting in a significance level of p<0.048 with Pre 2 only. No other between group differences were detected.

Total Number of Problem Behaviours (TN)

The total number of problem behaviours recorded on the ABC showed no significant differences between the groups at outset (medians 12 and 13, respectively). In Group A the scores decreased slightly, but this did not reach statistical significance. A small, but non-significant increase occurred in Group B between Pre 1 and Pre 2, which was followed by a decrease in score at Post. A significant change was detected between Pre 2 and Post (p<0.048), but not between Pre 1 and Post, which suggested some instability in the scores. No significant differences between the groups were found at any time point.

For the participants in the family homes the number of problem behaviours was generally lower than found in the staffed homes, especially for those in Group B (Group A = 11, Group B = 8.5). There was a non-significant decrease for the participants in Group A and a similar non-significant decrease for those in Group B between Pre 1 and 2. For those in Group B at Post there was a slight increase, with a significant change detected between Pre 1 and Post (p<0.032). At no time point were any significant between group differences detected for the family home groups.

In the staffed homes the total number of problem behaviours for the participants in the two groups were significantly different at baseline (p<0.021), with the Group B participants showing a higher median score of 19.5, compared with 12. For those in Group A the median score decreased slightly, but not significantly and some fluctuation in the scores was detected for the participants in Group B, which again was not significant. Although there was shown to be little within group change, significant differences were detected between the staffed home groups at all time points, none of these changes, however, could be attributed to an effect of the intervention.

Total Number of Severe Problem Behaviours (T3s)

The total number of severe problem behaviours was also recorded using the ABC (Table 7). At the outset and at each time point in the study no significant differences were observed between the two groups (median = 0 for both). Overtime, no significant changes were observed in either group, as the scores remained the same throughout. The same pattern was found for the family home groups and for those in the staffed homes, with the exception of Group B at Pre 2 where the median rose to 0.5 and dropped back down to 0 at Post.

3.3.4 Index of Participation in Domestic Life (IPDL)

The degree of participation in tasks around the home (IPDL) is shown in Table 10. The scores at baseline were similar in Group A (median = 9) and Group B (median 7.5) and no significant differences were found between them. In Group A, there was no change at Post, and in Group B no significant difference was found between Pre 1 and Pre 2, although the median increased to a 9 from then onwards. Group B at Post showed no change in median score, however, the mean scores indicated an increase, which was found to be significant at the level of $p<0.049$. A significant change was also detected between Pre 1 and Post at the level of $p<0.006$. As no intervention effect was found for Group A, the changes occurring for Group B may have resulted from other factors. At no time point were any significant between group differences identified.

The participants in the family homes had generally lower levels of engagement in domestic activity (medians 2 and 6, respectively). Those in Group A showed an increase in domestic activity after the intervention, which was significant at the level of $p<0.009$. A significant increase was also found for those in Group B ($p<0.043$) between Pre 1 and Pre 2, but not at Post, which suggests that the scores were unstable over time. No significant differences were detected between the family home groups.

In the staffed homes the participants showed higher levels of engagement in domestic tasks, with median scores of 10.5 (Group A) and 9.5 (Group B). The participants in Group A, showed a significant decrease at Post ($p<0.045$). For those in Group B the scores remained stable between Pre 1 and Pre 2 and then increased at Post, resulting in a significant change between Pre 1 and Post ($p<0.021$) and between Pre 2 and Post ($p<0.004$). A between group difference was also found at Post ($p<0.012$), which may be due to the different direction in the score change for the two staffed home groups. No other between group differences were identified at the other time points.

Table 16. Index of Participation in Domestic Life (IPDL and Choice Questionnaire (Choice)

Total Sample (TS) **Family Homes (FH)** **Staffed Homes (SH)**	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
IPDL TS **Mean** **Median** **(Range)**	N=105 8.68 9 (0-26)	N=105 8.72 9 (0-25)	N=82 8.49 7.5 (0-25)	N=82 8.84 9 (0-26)	N=82 9.67 9 (0-24) **1*2
IPDL FH **Mean** **Median** **(Range)**	N=33 5.67 2 (0-21)	N=33 7.55 4 (0-25) **	N=41 6.56 6 (0-25)	N=41 7.44 7 (0-26) *	N=41 7.27 7 (0-18)
IPDL SH **Mean** **Median** **(Range)**	N=65 9.42 10.5 (0-26)	N=65 8.12 9 (0-23) *	N=36 9.0 9.5 (0-20)	N=36 8.89 8.88 (0-21)	N=36 10.78 11 (0-21) *1 •2 +
Choice TS **Mean** **Median** **(Range)**	N=67 52.01 52 (32-72)	N=67 48.92 49 (35-74) ••	N=32 50.59 50.5 (31-63)	N=32 53.13 53 (40-67) ++	N=32 47.75 47 (35-66) •2
Choice FH **Mean** **Median** **(Range)**	-	-	-	-	-
Choice SH **Mean** **Median** **(Range)**	N=65 51.46 52 (32-72)	N=65 48.34 48 (35-74) •	N=32 50.59 50.5 (31-63)	N=32 53.13 53 (40-67) †	N=32 47.75 47 (35-66) •2

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

3.3.5 Choice Questionnaire (Choice)

The Choice Questionnaire was not appropriate for use in the family homes and therefore only the scores for the total sample and the staffed home groups are presented (Table 10). The subjects living independently are included in the total sample groups but not in the staffed home groups: no statistical differences were found between the groups (medians 52 and 50.5, respectively). The median scores in Group A decreased to 49, resulting in a significant change at the level of p<0.0001, which also reached the level of the Bonferroni Test. In Group B, the scores increased slightly between Pre 1 and Pre 2, but this did not achieve statistical significance suggesting stability in the scores. However, a significant between group difference was identified between Group A Post and Group B Pre 2 (p<0.005), which concurred with the decrease in scores in Group A and stability in the scores in Group B. At Post the scores in Group B also decreased with the significance level of p<0.001 being reached between Pre 2 and Post only. This may suggest a negative effect of the intervention, although the absence of a significant change between Pre 1 and Post in Group B weakens this possibility. In the staffed home groups the scores were very similar, except that without the scores from the individuals living independently the significance level decreased from p<0.0001 to p<0.001 in Group A. There was no difference for those in Group B as independent subjects were not included for Group B in the total sample.

3.3.6 Index of Community Involvement (ICI)

<u>Total Score for ICI</u>

The range of activity in the community was compared at baseline and no significant difference was found between Group A (median = 6), and Group B (median = 7). Over time, no significant change occurred for Group A (Table 11). In Group B, a slight increase in activity levels occurred between Pre 1 and Pre 2, and although this was not statistically significant in itself, it resulted in a significant between group difference with Group A at Pre (p<0.003) and at Post (p<0.0001). This change however, which reached the level of the Bonferroni Test, indicates instability in the scores. The scores then decreased at Post and a significant change was observed between Pre 2 and Post (p<0.012), which again suggests some random fluctuation in the scores for Group B.

In the family home groups there were no significant differences at the outset (medians 6 and 7 respectively). Those in Group A and Group B showed little change, although a between group difference was detected between Group B Pre 2 and those in Group A at Pre ($p<0.010$) and Post ($p<0.023$). This would suggest that a slight change had occurred at Pre 2 for those in Group B, with no other changes being evident at the other time points.

For the staffed homes, a slight but non-significant decrease occurred for those in Group A, and slight, but non-significant increase occurred for those in Group B between Pre 1 and Pre 2. A between group difference was detected at Pre 2 for the Group B participants with those in Group A at Post ($p<0.005$). The scores for the Group B participants decreased again at Post resulting in a statistically significant change between Pre 2 and Post ($p<0.006$), but not Pre 1 and Post, suggesting some instability in the scores rather than an effect of the intervention.

Frequency Score for ICI

The frequency of the use of community facilities was also recorded using the ICI (Table 11). At the outset similar scores were obtained and no statistical difference was found between the groups (medians 19 and 21, respectively). In Group A there was a slight decrease over time but this did not reach statistical significance. For Group B the scores rose at Pre 2 resulting in a significant change between Pre 1 and Pre 2 ($p<0.014$) and a between group difference with Group A Pre ($p<0.0001$) and Group A Post ($p<0.001$), reaching the level of the Bonferroni Test but indicating instability in the scores. At Post, there was a decrease for Group B that achieved a statistically significant change with Pre 2 ($p<0.032$), as well as a between group difference with Group A Post ($p<0.011$). Overall, the results indicate some random movement in the scores for Group B, but nothing to suggest an effect of the intervention.

Table 17. Index of Community Involvement (ICI)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ICI TS Mean Median (Range)	N=105 6.39 6 (0-12)	N=105 6.22 6 (0-13)	N=82 7.10 7 (2-12)	N=82 7.50 8 (3-12) †Pre ††Post	N=82 6.96 7 (3-14) *2
ICI FH Mean Median (Range)	N=33 5.61 6 (0-12)	N=33 5.82 6 (0-13)	N=41 6.78 7 (2-12)	N=41 7.27 7 (3-12) +Pre +Post	N=41 6.90 7 (3-14)
ICI SH Mean Median (Range)	N=65 6.86 7 (2-11)	N=65 6.38 6 (2-11)	N=36 7.39 7 (2-11)	N=36 7.69 8 (4-12) ++Post	N=36 6.89 7 (4-12) **2
ICI freq TS Mean Median (Range)	N=105 19.25 19 (0-43)	N=105 17.82 18 (0-45)	N=82 21.17 21 (2-41)	N=82 22.89 23 (4-38) * †Pre ††Post	N=82 21.15 21.5 (4-41) *2 +
ICI freq FH Mean Median (Range)	N=33 17.15 17 (0-43)	N=33 18.21 19 (0-45)	N=41 20.32 19 (5-35)	N=41 22.71 24 (4-38) * ++ Pre +Post	N=41 20.39 20 (4-35)
ICI freq SH Mean Median (Range)	N=65 20.40 20 (6-36)	N=65 17.03 17 (2-35) ••	N=36 22.19 22 (2-41)	N=36 22.75 22 (9-34) ††Post	N=36 21.56 22 (7-41) +

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

In the family homes slightly lower levels of use of community facilities were observed at baseline (medians 17 and 19 respectively). There was no significant difference between the family home groups at baseline and a slight but non significant increase was seen in Group A of the family homes. In Group B there was some fluctuation in the scores with an increase at Pre 2 followed by a decrease at Post. At Pre 2 in Group B of the family homes a within group change was found between Pre 1 and Pre 2 at the level of p<0.025. Between group differences were also found at this time point with Group A of the family homes at Pre (p<0.006) and Post (p<0.040). These results indicate instability in the scores and no intervention effect was observed.

For those in the staffed homes a relatively higher use of community facilities was noted at the outset (medians 20 and 22, respectively). For those in Group A, a decrease in the scores occurred which resulted in a significant change at the level of p<0.0001, reaching the level of the Bonferroni Test. For those in Group B, little change occurred over time with the median score remaining at 22 across all time points. Significant between group differences were detected between those in Group A at Post and those in Group B Pre 2 (p<0.0001) and Group B Post (p<0.015). The significant difference between Group A Post and Group B Pre 2 reached the Bonferroni significance level and reflects the decrease at Post in Group A, which also reached the same significance level.

3.3.7 Diary of Scheduled Activity (Diary)

<u>Energetic Activity (Diary A)</u>

The hours per week of energetic activity (e.g. swimming, aerobics) were recorded across a typical week for each subject (see Table 12) with similar scores obtained for the two groups at baseline (medians 0.25 and 0 respectively). In Group A the scores significantly decreased at Post at the level of p<0.0001 (above the Bonferroni Test level). Over time there was a slight change in the activity levels in Group B between Pre 1 and Pre 2, which reached statistical significance (p<0.023). A between group difference was also detected between Group A Pre and Group B Pre 2 (p<0.018), indicating instability in the scores in Group B.

In the family homes no significant difference was found between the groups at baseline (median = 0, for both). A significant decrease in energetic activity occurred for those in Group A between Pre and Post at the level of p<0.028. In Group B of the family homes no significant changes were identified, either across the time points or between the two family home groups.

Table 18. Diary of Scheduled Activity (Diary)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Diary A TS Mean Median (Range)	N=104 1.75 0.25 (0-13)	N=104 0.81 0 (0-5) ••	N=79 1.61 0 (0-18)	N=79 0.94 0 (0-6.5) * +Pre	N=79 1.16 0 (0-9.5)
Diary A FH Mean Median (Range)	N=34 1.21 0 (0-8)	N=34 0.56 0 (0-4.5)*	N=39 1.69 0 (0-18)	N=39 0.90 0 (0-6.5)	N=39 0.83 0 (0-9)
Diary A SH Mean Median (Range)	N=64 2.20 1 (0-13)	N=64 1.02 1 (0-5) **	N=35 1.71 1 (0-7.5)	N=35 1.13 0 (0-6)	N=35 1.69 0 (0-9.5)
Diary B TS Mean Median (Range)	N=104 13.9 13 (0-44)	N=104 9.28 6.25 (0-37.5) ••	N=79 15.40 13.5 (0-41)	N=79 10.18 8.5 (0-37) •• +Pre	N=79 8.14 5 (0-48) ••1 *2
Diary B FH Mean Median (Range)	N=34 9.18 7.75 (0-35)	N=34 5.91 3.25 (0-26)*	N=39 13.25 10 (0-40.5)	N=39 10.19 9 (0-36.5) +Post	N=39 7.15 4 (0-42) ••1 *2
Diary B SH Mean Median (Range)	N=64 16.25 15.25 (0-44)	N=64 10.72 8.5 (0-37.5) ••	N=35 17.41 18 (0-34.5)	N=35 9.87 8 (0-27) •• †Pre	N=36 7.58 6 (0-27) ••1

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

At the outset, the staffed home participants had generally higher levels of energetic activity (median = 1, for both). Those in Group A showed a decrease in activity levels, which is shown in the mean scores, at the level of $p<0.005$. Over time, the scores for those in Group B did not change significantly and at no time point did the family home groups differ statistically.

Physical Activity (Diary B)

Diary B refers to the amount of physical activity (e.g. housework, shopping, walking) recorded for subjects across a typical week (Table 12). At the outset the scores were similar across the two groups and no statistical difference was found between them (medians 13 and 13.5, respectively). Group A decreased at Post achieving a statistical level of $p<0.0001$ with a similar decrease shown in Group B at Pre 2 ($p<0.0001$), suggesting instability in the scores. At Post a significant change was detected with Pre 1 ($p<0.0001$) and Pre 2 ($p<0.013$), with the first passing the Bonferroni Test significance level. In addition a statistically significant between group difference was found between Group A Pre and Group B Pre 2 ($p<0.010$), which would concur with the within group changes and suggest a deterioration over time in activity levels, rather than an intervention effect.

At the outset generally lower levels of physical activity were found in the family home groups (medians 7.75 and 10, respectively). Physical activity for those in Group A decreased achieving statistical significance at the level of $p<0.010$. In Group B of the family homes the scores remained stable between Pre 1 and Pre 2 and decreased at Post resulting in a significant change with Pre 1 ($p<0.0001$) and Pre 2 ($p<0.023$). The change between Pre 1 and Post for those in Group B also reached the Bonferroni significance level. In addition, a significant difference was found between Group A Post and Group B Pre 2 ($p<0.011$) which would be expected, given the decrease in the scores for Group A and stability in Group B.

These results suggest a possible deterioration in the activity levels for the family home groups post intervention.

For the staffed home groups higher activity levels were found at baseline (medians 15.25 and 18, respectively). Group A of the family homes showed a significant decrease in activity at Post ($p<0.0001$) and a similar decrease occurred for those in Group B between Pre 1 and 2 ($p<0.0001$), with the Bonferroni Test level being reached in both instances. The participants in Group B showed a further significant decrease at Post ($p<0.0001$), which reached the Bonferroni test level and indicated a downward trend. A significant between group difference was also detected between Group A Pre and Group B Pre 2 ($p<0.003$), concurring with the suggestion of deterioration in activity over time rather than an intervention effect.

3.3.8 Epilepsy Outcome Scale (EOS)

The level of concern of the carers of the subjects with epilepsy was compared (Table 13) and no significant differences were found at baseline (medians 22 and 32.5, respectively). In Group A the scores increased noticeably, but this did not achieve statistical significance. In Group B there was some fluctuation in the scores but again no statistical differences were found, either across the time points or between the two groups. A similar pattern was found in the family home and the staffed home groups with some changes in the scores; these however, did not achieve statistical significance.

The raw data were re-examined to investigate the greater changes in the scores that did not achieve statistical significance. It was discovered that when applying the Wilcoxon Signed Ranks Test, roughly equal numbers were appearing on both sides of the rank for each comparison. For example, in Group A of the total sample, 9 cases showed an increase in carer concern and 11 showed a decrease, with the size of difference being similar across the cases. Although there were some large increases and decreases these were balanced out by the ranking of the scores, which may explain why the medians of the scores suggested a difference between them (median score Pre = 22, Post = 36). Similarly, for the staffed home Group B, the medians of the scores were noticeably different between Pre 1 (median = 32) and Pre 2 (median = 13), but the scores were not significantly different. In this instance, 5 cases showed an increase in carer concern and 5 a decrease (one case was a tie) with the end result of there being no significant difference between them.

3.3.9 Malaise Inventory (Malaise)

The level of carer physical and psychological malaise was measured using the Malaise Inventory. This scale was not appropriate for use in the staffed homes and so was administered only to the family home carers (Table 13). A score of 5 or more suggests a level of malaise indicating psychiatric disturbance, according to the author of the scale (Rutter 1970a) and thus, although there was no statistical difference between the two family home groups at baseline, the higher median score of 6 for those in Group A would place them as a group, above the cut off for psychiatric disturbance. For those in Group A there was no change over time and the scores remained above the psychiatric disturbance cut off. Similarly, for the Group B participants there were no significant changes over time, with the median scores for them as a group remaining below the psychiatric disturbance cut off. Therefore, although the two family home groups were not found to be statistically different, the use of the cut off indicates that a greater number of the Group A participants were found to be at risk of suffering from psychiatric disturbance, compared to the Group B participants.

When the individual scores were examined in detail, 21 (66%) participants in Group A had a score of 5 or above Pre intervention and 20 (63%) were above the cut off at Post. For those in Group B this percentage was lower, with 19 (49%) participants at Pre 1 and 17 (44%) at Pre 2 and Post. A significant difference at the level of p<0.045 was detected at Post between the two family home groups, but no other within group changes or between group differences were found.

Table 19. Epilepsy Outcome Scale (EOS), Malaise Inventory (Malaise) and Caregiver Strain Index (Carer Index)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS TS	N=21	N=21	N=16	N=16	N=16
Mean	43.1	44.52	37.25	27.69	31.94
Median	22	36	32.5	19.5	23
(Range)	(1-125)	(0-123)	(0-103)	(1-139)	(0-103)
EOS FH	N=12	N=12	N=5	N=5	N=5
Mean	37.92	38.58	46.80	46.40	49.80
Median	19.5	29.5	39	30	43
(Range)	(1-112)	(2-109)	(0-103)	(1-139)	(2-103)
EOS SH	N=8	N=8	N=11	N=11	N=11
Mean	50.75	57.75	32.91	19.18	23.82
Median	44	59	32	13	23
(Range)	(1-125)	(0-123)	(0-95)	(2-49)	(0-101)
Malaise FH	N=32	N=32	N=39	N=39	N=39
Mean	6.23	6	4.87	5.10	4.37
Median	6	6	4.5	4	4
(Range)	(0.5-15)	(0-16)	(0-15)	(0-14)	(0-13) +
Carer Index	N=32	N=32	N=38	N=38	N=38
FH Mean	5.58	4.72	4.68	4.29	3.12
Median	5	4.5	4	4	2
(Range)	(0-13)	(0-12) *	(0-13)	(0-12)	(0-12) **1 *2 +

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

3.3.10 Caregiver Strain Index (Carer Index)

Carers' strain levels were measured using the Caregiver Strain Index, which, like the Malaise Inventory was used only in the family homes (Table 13). The two family home groups were found to be similar at baseline and no significant differences were found between them (medians 5 and 4, respectively). For those in Group A there was a decrease in strain levels reported over time resulting in a significant change at $p<0.017$. For Group B participants, stability was evident in the scores between Pre 1 and Pre 2, with a slight but non significant decrease occurring followed by a greater decrease at Post which was significantly different from both Pre 1 ($p<0.007$) and Pre 2 ($p<0.023$). A between group difference was also found between Group A Post and Group B Post ($p<0.026$) but the comparison of Group A Post and Group B Pre 2 did not achieve statistical significance. The results suggest a possible effect of the intervention, in terms of a change occurring at Post for those in both family home groups with stability demonstrated prior to the intervention for those in Group B. However, a significant change between Group A at Post and Group B Pre 2 would have been expected if an intervention effect had occurred and the two groups were found to be significantly different at Post. Therefore, although an intervention effect is suggested by the pattern of within group change the between group differences throw some doubt on whether the changes can be attributed to an effect of the intervention.

3.3.11 Maslach Burnout Inventory (Maslach)

The level at which paid carers were suffering from emotional exhaustion and cynicism, otherwise described as the syndrome of "burnout" was measured on the three subscales: Emotional Exhaustion, Depersonalization and Personal Achievement of the Maslach Burnout

Inventory. The frequency and intensity of burnout is measured separately, resulting in six separate scores. The Maslach was administered only in staffed homes, as it is not appropriate for use in the family homes (Table 14). The scores were also categorised into low, moderate and high levels of "burnout", for both individuals and for each group. In addition, normative data reported by the authors using a sample group of professionals working in human services was also used, for comparison against the group scores. In some instances carers were responsible for more than one patient, thus, the number of carers on which information could be collected was reduced. There were only 4 such cases in Group B, therefore, the Wilcoxon Signed-Ranks Test could not be performed. The Mann Whitney U Test can be used on smaller numbers and thus comparisons between the two groups were possible.

Emotional Exhaustion (Emot Ex)

No significant differences were detected between the staffed home groups at baseline, for emotional exhaustion frequency (medians 10.34 and 10.5, respectively) or emotional exhaustion intensity (medians 13.7 and 14.35, respectively). Group A of the staffed homes showed a significant increase in the frequency of emotional exhaustion at $p<0.028$ and a significant increase in the intensity of emotional exhaustion ($p<0.003$). No comparisons could be made with Group B participants due small numbers. At no time point were any significant differences detected between the two staffed home groups.

Using the "burnout" categories suggested by the authors, the frequency of emotional exhaustion for those in Group A changed from low to medium at Post, and, for those in Group B the scores remained in the category of low between Pre 1 and Pre 2, but changed to medium at post. For intensity of emotional exhaustion, the two staffed home groups remained in the category of low both at Pre and at Post. When compared to the normative data, both staffed home groups, at all time points were below the mean of 24.08, for frequency of emotional exhaustion. The staffed home groups were also below the mean of 31.68 for intensity of emotional exhaustion, indicating that the carers on the study were not likely to suffer from "burnout" due to emotional exhaustion.

Depersonalization (Depers)

At baseline no significant difference was detected between the two staffed home groups on depersonalization frequency (medians 2.4 and 3, respectively), or intensity (3.5 and 5.85, respectively). Both frequency and intensity increased slightly for those in Group A at Post, but neither was found to show a significant change. For the participants in Group B some fluctuation was evident, but it was not possible to statistically test this due to the small numbers. At any of the time points no significant differences were identified between the two groups.

The authors' "burnout" categories showed the level of depersonalization to be low for both staffed home groups, with no changes at Pre or at Post. When compared to the normative data the level of depersonalisation remained well below the mean of 9.40 for frequency and 11.71 for intensity; again indicating a low level of "burnout" among the study group

Personal Accomplishment

At the outset no significant differences were detected between the two staffed home groups for frequency (medians 38.17 and 37.8, respectively) or intensity (medians 37.5 and 37.7, respectively). Little change was evident for those in Group A, with a slight but non-significant decrease for frequency of personal accomplishment, and a slight increase for intensity of personal accomplishment. Group B participants showed some fluctuation in the scores for frequency, with an increase at Pre 2, followed by a decrease at Post, and a small decreasing trend over the time points for intensity of personal accomplishment. Within group comparisons were not possible and no significant differences were detected between the two staffed home groups at any time point.

Table 20. Maslach Burnout Inventory (Maslach)

Total Sample (TS) **Family Homes (FH)** **Staffed Homes (SH)**	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Emot Ex Freq SH **Mean** **Median** **(Range)**	N=12 10.81 10.34 (1.5-21.4)	N=12 18.38 18.17 (6-32) *	N=4 11.93 10.5 (6-20.7)	N=4 9.53 9.4 (6.3-13)	N=4 17.95 17.7 (11-25.4)
Emot Ex Inten SH **Mean** **Median** **(Range)**	N=11 14.76 13.7 (7-22.5)	N=11 24.08 22.33 (13.7-36) •	N=4 14.68 14.35 (5-25)	N=4 17.85 17.2 (10.6-26.4)	N=4 24.60 23.5 (14-37.4)
Depers Freq SH **Mean** **Median** **(Range)**	N=12 3.55 2.4 (0-8.4)	N=12 3.14 3.34 (0-7)	N=4 2.75 3 (0.7-4.3)	N=4 0.75 0.5 (0-2)	N=4 1.68 0.65 (0-5.4)
Depers Inten SH **Mean** **Median** **(Range)**	N=11 4.54 3.5 (0-8.4)	N=11 4.72 5 (0-12.7)	N=4 6.08 5.85 (4-8.6)	N=4 3.5 1 (0-12)	N=4 3.43 3.85 (0-6)
Pers Acc Freq SH **Mean** **Median** **(Range)**	N=12 38.9 38.17 (33-45)	N=12 36.98 36.2 (28.67-46)	N=4 37.92 37.8 (32.4-43.7)	N=4 39.85 39.65 (36.4-43.7)	N=4 37.63 36.9 (35.3-41.4)
Pers Acc Inten SH **Mean** **Median** **(Range)**	N=10 37.79 37.5 (33-43)	N=10 38.49 37.7 (32-49)	N=4 40.43 40 (34-47.7)	N=4 39 39.5 (36.3-40.7)	N=4 38.8 39 (33.7-43.5)

*	Significant within group change at $p<0.05$	+	Significant between group difference at $p<0.05$
**	Significant within group change at $p<0.01$	++	Significant between group difference at $p<0.01$
•	Significant within group change at $p<0.005$	†	Significant between group difference at $p<0.005$
••	Significant within group change at $p<0.001$	††	Significant between group difference at $p<0.001$

The categories given by the authors showed a moderate level of personal accomplishment for both frequency and intensity at all time points, for both staffed home groups. One exception was noted for the frequency of personal accomplishment for those in Group B at Pre 2 where the scores fell into the low category, suggesting a decrease in the indication of "burnout" in terms of a higher level of personal accomplishment for the participants of Group B at this time. For the frequency of personal accomplishment the participants in both staffed home groups were above the mean for the normative data of 36.01, but for intensity, only the participants in Group B were above the mean of 39.70. This suggests that lack of personal accomplishment might put the study group of carers at risk for "burnout" particularly those in Group B. However, the low scores on the other two categories indicate that overall the risk is low for both groups.

3.3.12 SF-36 Carer

Physical Function (PF)

For the carers any limitation in performing physical activity was measured using the Physical Function subscale of the SF-36 (Table 15). At baseline the scores for the two groups were similar and no significant differences were found between them (medians 85 and 85, respectively). In Group A, no significant change occurred and in Group B the scores remained stable between Pre 1 and Pre 2 with no significant changes detected at Post. At no time point did either of the groups differ significantly.

A generally lower level of physical functioning was found for the carers in the family home groups (medians 62.5 and 80, respectively). No significant differences were detected between the family home groups at the outset, or at any other time point and no significant within group changes were found in either group.

For the staffed homes higher levels of carer physical functioning were apparent at baseline (medians 95 and 97.5). The scores decreased a little at Post for those in Group A and there was some fluctuation for those in Group B. None of these changes achieved statistical significance, however, and no significant differences were found between the two groups at any time point.

Table 21. SF-36 Carer - Subscales Physical Function (PF) and Role Physical (RP)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer TS Mean Median (Range)	N=55 74.27 85 (5-100)	N=55 71.18 85 (0-100)	N=56 73.39 85 (0-100)	N=56 78.93 90 (0-100)	N=56 76.88 90 (0-100)
PF Carer FH Mean Median (Range)	N=32 61.41 62.5 (5-100)	N=32 58.13 52.5 (0-100)	N=40 67.88 80 (0-100)	N=40 72.25 80 (0-100)	N=40 69.88 75 (0-100)
PF Carer SH Mean Median (Range)	N=23 92.17 95 (65-100)	N=23 89.35 90 (45-100)	N=16 87.19 97.5 (20-100)	N=16 95.63 100 (80-100)	N=16 94.38 95 (80-100)
RP Carer TS Mean Median (Range)	N=56 65.27 100 (0-100)	N=56 64.29 87.5 (0-100)	N=56 65.63 100 (0-100)	N=56 70.54 100 (0-100)	N=56 79.02 100 (0-100) *1
RP Carer FH Mean Median (Range)	N=33 49.39 50 (0-100)	N=33 50.76 50 (0-100)	N=40 58.13 50 (0-100)	N=40 66.25 100 (0-100)	N=40 74.38 100 (0-100) *1 +
RP Carer SH Mean Median (Range)	N=23 88.04 100 (0-100)	N=23 83.69 100 (0-100)	N=16 84.38 100 (0-100)	N=16 81.25 100 (0-100)	N=16 90.63 100 (50-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Role Physical (RP)

Problems with work or daily activities as a result of physical health were measured for the carers using the Role Physical subscale of the SF-36 (Table 15). The two groups were found not to differ significantly at the outset (median = 100 for both). In Group A, the scores decreased slightly at Post but did not reach a significance level. There was very little change in the scores for Group B but a statistically significant change was identified between Pre 1 and Post at the level of $p<0.015$ with the mean scores suggesting a reduction and, therefore instability over time. No between group differences were found throughout.

The carers in the family homes had similar levels of difficulties with work related activities at baseline in the two groups. The amount of difficulty with work and daily activities, however, was noticeably lower in the family homes (median for both = 50). There was little change in the scores for those in Group A, with a slight increase for the Group B participants between Pre 1 and Pre 2, which was maintained at Post. This resulted in a statistically significant change between Pre 1 and Post at the level of $p<0.017$; but not between Pre 2 and Post. A statistically significant between group difference was identified between Group A Post and Group B Post at the level of $p<0.018$. However, these changes are more likely to be as a result of general change over time than any effect of the intervention.

The carers in the staffed home groups had generally higher scores at baseline and no significant differences were found between them (median = 100 for both). Over time, there was little change for those in either group and no significant differences between them were found at any of the time points.

Bodily Pain (BP)

The levels of bodily pain for the carers in the two groups were compared (Table 16); no statistical differences were found between them (Group A = 62, Group B = 64). The scores for those in Group A remained relatively the same at Post and no statistical change was identified. In Group B, there was some movement in the scores with a decrease at Pre 2 and a small increase at Post, however none of these changes achieved statistical significance. A between group difference was found between Group A Post and Group B Post at the level of ($p<0.038$), but no other significant differences were found at any of the other time points.

For the family home carers, there was a difference between the two groups at baseline but this did not reach a level of significance (medians 51 and 62, respectively). In Group A of the family homes, despite a decrease in the scores at Post, there was no significant change. For those in Group B, there was an increase in the scores at Pre 2 which, although not resulting in a significant change with Pre 1, did achieve significance when compared to those in Group A, at both Pre ($p<0.048$) and Post ($p<0.040$). Also at Post for the Group B participants, a between group difference was found with those in Group A, suggesting that a slight increase had occurred for those in Group B over time.

In the staffed homes, the carers had generally higher levels of bodily pain than the family home carers (medians 72 and 68, respectively). At the outset, no significant differences were found between the two groups. In Group A of the staffed homes, some change occurred, but statistical significance was not reached. For those in Group B, the scores fluctuated over time, but, again, no statistically significant changes were found. At none of the time points did the two groups differ significantly.

Table 22. SF-36 Carer - Subscales Bodily Pain (BP) and General Health (GH)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
BP Carer TS Mean Median (Range)	N=56 62.02 62 (0-100)	N=56 61.84 62 (0-100)	N=57 65.70 64 (0-100)	N=57 69.79 80 (0-100)	N=57 72.37 84 (0-100) +
BP Carer FH Mean Median (Range)	N=33 52.52 51 (0-100)	N=33 52.94 41 (0-100)	N=41 64.49 62 (0-100)	N=41 66.32 80 (0-100) +pre +post	N=41 68.44 74 (0-100) +
BP Carer SH Mean Median (Range)	N=23 75.65 72 (31-100)	N=23 74.61 82 (41-100)	N=16 68.81 68 (0-100)	N=16 78.69 79 (41-100)	N=16 82.44 84 (22-100)
GH Carer TS Mean Median (Range)	N=55 62.16 62 (8-100)	N=55 59.27 62 (5-100)	N=53 59.02 67 (0-100)	N=53 65.09 72 (10-100)	N=53 67.49 72 (10-100) •1
GH Carer FH Mean Median (Range)	N=33 53.76 60 (8-92)	N=33 53.64 55 (5-97)	N=38 56 64.5 (0-100)	N=38 62.45 65 (10-97)	N=38 63.87 63.5 (10-100) **1
GH Carer SH Mean Median (Range)	N=22 74.77 72 (50-100)	N=22 67.73 74.5 (15-100)	N=15 66.67 72 (25-100)	N=15 71.8 77 (30-100)	N=15 76.67 77 (40-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

General Health (GH)

The perceived health of the carers was measured using the general health subscale of the SF-36 (Table 16). The two groups were compared at baseline and no statistically significant differences were found between them (Group A = 62 and Group B = 67). In Group A, no significant change was shown at Post and also no change was found in Group B between Pre 1 and Pre 2. A significant change was found between Pre 1 and Post scores at the level of p<0.001, which reached the Bonferroni Test significance level. However, there was no significant change between Pre 2 and Post suggesting that the change had occurred over time, rather than as an effect of the intervention. No between group differences were found at any of the time points.

In the family home groups, the perceived health of the carers was found to be similar and no significant differences were identified between them (medians 60 and 64.5, respectively). A small change occurred for those in Group A, but this did not achieve statistical significance. The perceived health of those in Group B fluctuated slightly, resulting in a significant change between Pre 1 and Post ($p<0.006$), but not with Pre 2 and Post. This would indicate instability in the scores for those in Group B, rather than any effect of the intervention. At no time point were any significant differences found between the two family home groups.

Slightly higher levels of general health were observed in both groups for the participants in the staffed homes (median = 72 for both). No significant change over time occurred for those in Group A. A small but non-significant change occurred for those in Group B between Pre 1 and Pre 2 with the scores remaining stable at Post. No significant differences were found between the two staffed home groups at any time point.

Vitality (VT)

The vitality subscale of the SF-36 was used to measure carer's perceived energy levels and fatigue (Table 17). The perceived vitality of the carers in the two groups was found to be similar at baseline and no statistical differences were found (Group A = 60, Group B = 62.5). A slight decrease in scores occurred for Group A, but this was not shown to be statistically significant. In Group B there was a slight non-significant decrease at Pre 2 followed by stability in the scores at Post. No statistically significant differences were found between the two groups at any of the time points.

For the carers in the family homes the two groups were found to be statistically different at baseline (Group A = 45, Group B = 62.5), with the carers in Group B showing higher vitality levels compared to those in Group A ($p<0.030$). There was little change for Group A participants and for those in Group B no statistically significant changes were found. At Pre 2 the participants in Group B were found to be significantly different from those in Group A ($p<0.040$), but not at Post, which was probably due to the differences found between the two groups at baseline.

The staffed home carers had similar levels of energy and fatigue at the outset and no statistical differences between the two groups were found (medians 75 and 60, respectively). The participants in Group A showed a decrease in vitality levels post intervention, which achieved the significance level of $p<0.007$. The scores for those in Group B appeared to remain stable between Pre 1 and Pre 2 with a non-significant increase at Post. A between group difference was identified, however, between Group A Pre and Group B Post at the level of $p<0.007$, suggesting instability in the scores for those in Group B.

<u>Social Functioning (SF)</u>

The perceived quality and quantity of the social activities of the carers was measured using the social functioning subscale of the SF-26 (Table 17). Although, at baseline the carers in Group A presented a higher median score for social activity (median = 100) than those in Group B (median 87.5), this was not found to be significantly different. A small decrease occurred in the scores for Group A, but this did not achieve statistical significance. In Group

B, the scores decreased between Pre 1 and Pre 2 and then rose at Post, resulting in a significant change between Pre 2 and Post only (p<0.027). Between Group A Pre and Group B Pre 2 a significant difference was also detected at the level of p<0.021. These results indicate some movement in the scores for Group B, but no intervention effect.

Table 23. SF-36 Carer - Subscales Vitality (VT) and Social Functioning (SF)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
VT Carer TS	N=55	N=55	N=54	N=54	N=54
Mean	57.91	51.64	58.70	57.31	58.70
Median	60	55	62.5	60	60
(Range)	(5-100)	(0-95)	(10-100)	(5-90)	(10-95)
VT Carer FH	N=33	N=33	N=40	N=40	N=40
Mean	46.67	46.36	57.88	57.13	57
Median	45	50	62.5	57.5	60
(Range)	(5-85)	(0-95)	(10-100) +	(5-90) +Pre	(15-95)
VT Carer SH	N=22	N=22	N=14	N=14	N=14
Mean	74.77	59.55	61.07	57.86	63.57
Median	75	65	60	60	67.5
(Range)	(55-100)	(10-85) **	(20-90)	(25-80) ++Pre	(10-85)
SF Carer TS	N=56	N=56	N=56	N=56	N=56
Mean	81.25	75.44	75.0	73.88	81.47
Median	100	87.5	87.5	75	87.5
(Range)	(0-100)	(0-100)	(12.5-100)	(0-100) +Pre	(0-100) *2
SF Carer FH	N=33	N=33	N=40	N=40	N=40
Mean	75.0	70.83	73.44	72.5	82.5
Median	87.5	75	75	75	100
(Range)	(0-100)	(0-100)	(12.5-100)	(0-100)	(0-100) *1**2
SF Carer SH	N=23	N=23	N=16	N=16	N=16
Mean	90.22	82.07	78.91	77.34	78.91
Median	100	100	87.5	75	87.5
(Range)	(50-100)	(12.5-100)	(25-100)	(25-100) +Pre	(25-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

The participants in the family homes had relatively similar scores and no statistical differences were found between the two groups at baseline (medians 87.5 and 75, respectively). A small but non-significant decrease occurred over time for those in Group A. In Group B, the scores remained stable between Pre1 and Pre 2, with an increase at Post. This resulted in a significant difference between Pre 1 and Post ($p<0.019$) and Pre 2 and Post ($p<0.006$). Although there may have been a possible effect of the intervention for those in Group B, due to the absence of a similar pattern for the Group A participants, it is inconclusive. No between group differences were identified at any of the time points.

For those in the staffed homes, no statistical difference was identified between the groups at the outset (Group A =100, Group B 87.5). The scores for participants in Group A showed no significant change over time and for those in Group B there was no statistical change, despite some fluctuation in the scores. A significant difference was detected between those in Group A at Pre and those in Group B at Pre 2 ($p<0.017$), which would indicate some instability in the scores for the Group B participants.

Role Emotional (RE)

Carer difficulty with work or daily activities, due to mental health problems, was measured using the role emotional subscale of the SF-36 (Table 18). At baseline, the two groups were found to have similar scores and no significant difference was found between them (median = 100 for both). There was very little change in the two groups over time and no significant changes were identified. There were no significant between group differences identified at any of the time points.

For those in the family homes the pattern of results was very similar to that of the total sample. The family home groups were found to be similar at baseline (median = 100 for both) and no significant changes occurred for those in either group. Likewise, at no time point were the two family home groups found to differ significantly.

In the staffed homes a significant difference was found between the two groups at baseline (median 100 for both groups) reaching a significance level of $p<0.019$. In Group A, the mean scores (Pre = 98.55, Post = 78.26) indicated a decrease between Pre and Post at the level of $p<0.026$. For those in Group B, no significant changes were identified but a between group difference was found at Pre 2 with those in Group A at Pre ($p<0.0001$), which reached the significance level for the Bonferroni Test. No comparisons could be made, however, between the two staffed home groups, as they were not comparable at baseline.

Mental Health (MH)

The mental health subscale was the only measure to show between group differences in the total sample at the outset. For this reason a subgroup was formed by removing one outlier which reduced the number of subjects in Group 2 from 54 to 53. The scores in italics are the original scores before the outlier was removed and are given for clarity in the tables (Table 18, italics). The scores in normal text indicate the scores for the subgroup and it is these that will be discussed in detail (Table 18).

The revised scores for carer mental health were not statistically different at baseline (medians 80 and 76, respectively). In Group A and in Group B no statistical within group changes occurred over time. A significant between group difference was detected between Group A Pre and Group B Pre 2 at the level of $p<0.026$, indicating instability in the scores for Group B.

Table 24. SF-36 Carer - Subscales Role Emotional (RE) and Mental Health (MH)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
RE Carer TS Mean Median (Range)	N=51 84.31 100 (0-100)	N=51 73.2 100 (0-100)	N=50 76 100 (0-100)	N=50 74 100 (0-100)	N=50 83.33 100 (0-100)
RE Carer FH Mean Median (Range)	N=28 72.62 100 (0-100)	N=28 69.05 100 (0-100)	N=34 75.49 100 (0-100)	N=34 76.47 100 (0-100)	N=34 79.41 100 (0-100)
RE Carer SH Mean Median (Range)	N=23 98.55 100 (66.67-100)	N=23 78.26 100 (0-100) *	N=16 77.08 100 (0-100) +	N=16 68.75 66.67 (0-100) ††Pre	N=16 91.67 100 (0-100)
MH Carer TS Mean Median (Range)	N=55 76.8 80 (32-100)	N=55 72.44 76 (4-100)	N=53 72.83 76 (36-96)	N=53 71.25 72 (36-100) +Pre	N=53 75.02 76 (36-100)
MH Carer FH Mean Median (Range)	N=33 71.03 72 (32-100)	N=33 70.79 76 (4-100)	N=40 73.0 76 (36-96)	N=40 72.5 74 (36-100)	N=40 75.1 76 (36-100)
MH Carer SH Mean Median (Range)	N=22 85.45 84 (60-100)	N=22 74.91 78 (28-100) *	N=13 72.01 72 (48-96) +	N=13 67.38 68 (44-96) ††Pre	N=13 74.77 76 (36-100)
MH Carer TS *Mean* *Median* *(Range)*	*N=55* *76.8* *80* *(32-100)*	*N=55* *72.44* *76* *(4-100)*	*N=54* *71.85* *74* *(20-96)* +	*N=54* *70.67* *72* *(36-100)* +Pre	*N=54* *75.26* *76* *(36-100)*
MH Carer FH *Mean* *Median* *(Range)*	*N=33* *71.03* *72* *(32-100)*	*N=33* *70.79* *76* *(4-100)*	*N=40* *73.0* *76* *(36-96)*	*N=40* *72.5* *74* *(36-100)*	*N=40* *75.1* *76* *(36-100)*
MH Carer SH *Mean* *Median* *(Range)*	*N=22* *85.45* *84* *(60-100)*	*N=22* *74.91* *78* *(28-100)* *	*N=14* *68.57* *68* *(20-96)* ++	*N=14* *65.43* *68* *(44-96) †† Pre*	*N=14* *75.71* *78* *(36-100)*

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

For those in the family homes, the two groups were not found to be statistically different at the outset (Group A = 72, Group B = 76). There was little change over time for those in

Group A, and for Group B participants there was some fluctuation; but this did not reach statistical significance. At no time point did the two family home groups differ significantly.

In the staffed homes the two groups were statistically different at baseline (medians 84 and 72 respectively) at a significance level of p<0.013. The scores for those in Group A then decreased at Post with a significant change at the level of p<0.023. The scores for the participants in Group B fluctuated a little over time but none of the changes were found to be significant. A between group difference was found between Group A Pre and Group B Pre 2 at the level of p<0.0001, which reached the level of the Bonferroni Test. No comparisons could be made between the two staffed home groups due to the difference between them at baseline.

3.3.13 SF-36 Subject

Physical Functioning

At the outset, the level of the subjects' physical ability was similar across the two groups (Table 19) and no significant difference was detected between them (medians 67.5 and 75, respectively). Both groups showed a slight downward trend over time but no significant change was detected in either Group A or Group B and at no time point was either of the groups found to differ significantly.

In the family homes, the groups were found to be different from the outset (Group A = 30, Group B = 70) at the significance level of p<0.014. Over time, the Group A participants showed a significant decrease (p<0.048); this was not the case for those in Group B whose scores remained relatively stable over time. A significant between group difference was identified at Pre 2 for those in Group B when compared to the scores at Pre for the Group A participants, which was likely due to the differences between the groups at baseline.

Table 25. SF-36 Subject - Subscales Physical Function (PF) and Role Physical (RP)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Subject TS Mean Median (Range)	N=104 54.58 67.5 (0-100)	N=104 56.25 55 (0-100)	N=81 63.21 75 (0-100)	N=81 63.33 70 (0-100)	N=81 59.14 65 (0-100)
PF Subject FH Mean Median (Range)	N=33 39.58 30 (0-100)	N=33 46.82 45 (0-100) *	N=39 62.95 70 (0-100) +	N=39 61.28 70 (0-100) +Pre	N=39 58.97 65 (0-100)
PF Subject SH Mean Median (Range)	N=65 61.62 70 (0-100)	N=65 59.85 65 (0-100)	N=36 63.75 75 (0-100)	N=36 65.42 77.5 (0-100)	N=36 60.56 65 (0-100)
RP Subject TS Mean Median (Range)	N=104 72.12 100 (0-100)	N=104 78.13 100 (0-100)	N=79 73.73 100 (0-100)	N=79 76.27 100 (0-100)	N=79 73.73 100 (0-100)
RP Subject FH Mean Median (Range)	N=33 58.33 75 (0-100)	N=33 66.67 100 (0-100)	N=37 70.27 100 (0-100)	N=37 72.30 100 (0-100)	N=37 72.97 100 (0-100)
RP Subject SH Mean Median (Range)	N=65 80.0 100 (0-100)	N=66 83.33 100 (0-100)	N=36 81.94 100 (0-100)	N=36 83.33 100 (0-100)	N=36 77.78 100 (0-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

For the staffed homes the two groups were not significantly different at baseline (medians 70 and 75, respectively). Little change was apparent in either staffed home group and no significant within group changes were detected. Over time no significant differences were identified between the two staffed home groups.

Role Physical

At baseline, the ability levels of physical activity were compared (Table 19) and no significant differences were found between the two groups (median = 100 for both). In both groups no significant changes were detected over time and between the groups no significant differences were found at any of the time points. A similar pattern was shown both for the family home and the staffed home groups, with no significant within group changes or between group differences being identified.

Bodily Pain (BP)

The level of bodily pain for the subjects was similar in both groups (median = 84 for both) and no significant difference was found between them (Table 20). Over time little change was evident in either group and no significant differences were detected between the groups at any time point.

In the family homes, the two groups were not found to be significantly different at baseline, although a large difference could be seen between the median scores (Group A = 63, Group B = 100). A further examination of the raw data revealed that a similar number of subjects in both groups were scoring at the top end of the scale, which is reflected in the mean scores for the family home groups (means 64.60 and 74.08, respectively). Thus, even though the number of participants scoring 100 in Group B was higher (18 subjects), when the number of subjects scoring 60 and above was compared, this accounted for 22 of the subjects in Group A and 26 of the subjects in Group B.

No significant change was found for those in Group A over time and for the Group B participants the scores remained stable between Pre 1 and Pre 2. A between group difference was identified at Pre 2 for those in Group B when compared with the scores at Pre for the Group A participants at the level of p<0.019. At Post for those in Group B there was an increase which resulted in a significant change with Pre 1 (p<0.048) and a between group difference with those in Group A at Post. These results would suggest some instability in the scores for those in Group B over time.

Table 26. SF-36 Subject – Subscales Bodily Pain (BP) and General Health (GH)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
BP Subject TS Mean Median (Range)	N=104 73.80 84 (0-100)	N=104 77.34 84 (0-100)	N=76 74.84 84 (0-100)	N=76 78.45 84 (0-100)	N=76 77.14 84 (2.5-100)
BP Subject FH Mean Median (Range)	N=34 64.60 63 (0-100)	N=34 69.88 79.5 (0-100)	N=37 74.08 100 (0-100)	N=37 78.45 84 (2.5-100) +Pre	N=37 84.11 100 (41-100) *1 +
BP Subject SH Mean Median (Range)	N=64 79.14 84 (12-100)	N=64 80.63 84 (22-100)	N=33 80.48 88 (24-100)	N=33 82.15 84 (41-100)	N=33 75.23 84 (2.5-100)
GH Subject TS Mean Median (Range)	N=91 58.83 62 (0-100)	N=91 59.57 67 (5-100)	N=70 64.76 67 (15-100)	N=70 64.09 67 (10-100)	N=70 67.54 70 (20-100)
GH Subject FH Mean Median (Range)	N=26 53.22 54.5 (5-97)	N=26 56.19 58.5 (5-100)	N=36 63.33 58.5 (25-100)	N=36 65.33 67 (10-100)	N=36 69.94 77 (20-100)
GH Subject SH Mean Median (Range)	N=59 62.81 70 (0-100)	N=59 62.27 67 (15-100)	N=28 69 72 (20-97)	N=28 64.29 67 (30-92)	N=28 66.27 67.5 (25-97)

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

At the outset, the staffed home groups were found to be similar (medians 84 and 88, respectively). The two groups showed only slight change over time and no significant results were detected. At no time point were either of the staffed home groups found to be significantly different.

General Health (GH)

The subjects' level of general health was compared at the outset (Table 20) and no significant differences were detected between the two groups (medians 62 and 67, respectively). Little change was evident in the groups across the time points and no significant within group change was detected. Between the groups no significant differences were found throughout. A similar pattern was shown for both the family home and the staffed home groups with no significant change identified.

Vitality (VT)

Similar baseline vitality scores were obtained for the two groups (medians 55 and 60, respectively) and no significant differences were found between them (Table 21). Little change occurred over time in either group and no significant within-group differences were found. At no time point was either of the groups shown to differ significantly.

For the family home groups, a between group difference was found at baseline (Group A = 50 and Group B = 60) that was significant at the level of $p<0.042$. A significant increase occurred for the participants in Group A ($p<0.007$) with the scores for those in Group B remaining stable between Pre 1 and Pre 2. A between group difference was detected at Pre 2 for those in Group B when compared to those in Group A at Pre ($p<0.042$). For the Group B participants an increase occurred at post resulting in a significant change with Pre 1 at the level of p<0.021. No comparisons could however be made between the two family home groups due to the differences shown at baseline.

Table 27. SF-36 Subject – Subscales Vitality (VT) and Social Functioning (SF)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group 1		Group 2		
	Pre	Post	Pre 1	Pre 2	Post
VT Subject TS Mean Median (Range)	N=92 55.67 55 (5-100)	N=92 58.48 60 (5-90)	N=70 60.21 60 (5-100)	N=70 61 62.5 (10-100)	N=70 63.79 65 (5-100)
VT Subject FH Mean Median (Range)	N=27 49.54 50 (5-80)	N=27 63.15 60 (35-90) **	N=36 60.97 60 (5-100) +	N=36 63.33 65 (10-100) ++Pre	N=36 68.47 75 (10-100) *1
VT Subject SH Mean Median (Range)	N=59 59.32 60 (15-100)	N=59 56.78 60 (5-90)	N=28 61.07 60 (20-90)	N=28 59.64 65 (20-85)	N=28 59.46 60 (5-95)
SF Subject TS Mean Median (Range)	N=105 77.74 87.5 (0-100)	N=105 80.12 100 (0-100)	N=80 76.09 87.5 (12.5-100)	N=80 77.34 87.5 (0-100)	N=80 83.28 100 (0-100) *1
SF Subject FH Mean Median (Range)	N=34 72.43 87.5 (0-100)	N=34 74.26 87.5 (0-100)	N=40 73.44 87.5 (12.5-100)	N=40 78.75 93.75 (12.5-100)	N=40 87.20 100 (25-100) **1 *2
SF Subject SH Mean Median (Range)	N=65 80.19 87.5 (12.5-100)	N=65 81.92 100 (0-100)	N=34 82.35 100 (25-100)	N=34 78.68 93.75 (37.5-100)	N=34 82.35 87.5 (0-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

The staffed home groups had similar scores at baseline (median = 60 for both). Both groups maintained similar scores and no significant changes were detected over time. Between the groups no significant differences were found at any of the time points.

Social Functioning (SF)

The social functioning scores for the two groups were found to be similar at the outset (median = 87.5 for both) and no significant differences were detected (Table 21). Group A showed a slight but non-significant increase at Post with Group B remaining stable between Pre 1 and Pre 2. Group B increased at Post resulting in a significant change with Pre 1 ($p<0.025$), but not Pre 2, suggesting change over time rather than an effect of the intervention. At no time point were any between group differences identified.

Those in the family homes showed similar levels of social functioning at baseline (median 87.5 for both). Little change was evident for those in Group A and statistical significance was not achieved. For those in Group B, stability was maintained between Pre 1 and Pre 2 with an increase at Post resulting in a significant change with Pre 1 ($p<0.006$) and Pre 2 ($p<0.043$). Throughout, no significant between group differences were detected between the family home groups.

At the outset, the staffed home participants were not significantly different (medians 87.5 and 100, respectively). Those in Group A showed a slight increase at Post, but this was not statistically significant. The Group B participants showed a gradual decrease over time, but again statistical significance was not achieved. At no time point did the staffed home groups differ significantly.

Role Emotional (RE)

At baseline, any limitations due to mental health problems were compared (Table 22) and no significant difference was found between the two groups (median = 100, for both). Little change was evident for those in either group over time and at no time point were the two groups found to differ significantly.

Table 28. SF-36 Subject – Role Emotional (RE) and Mental Health (MH)

Total Sample (TS) Family Homes (FH) Staffed Homes (SH)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
RE Subject TS Mean Median (Range)	N=102 75.82 100 (0-100)	N=102 83.66 100 (0-100)	N=76 80.70 100 (0-100)	N=76 77.63 100 (0-100)	N=76 83.33 100 (0-100)
RE Subject FH Mean Median (Range)	N=32 77.08 100 (0-100)	N=32 90.63 100 (0-100) *	N=36 83.33 100 (0-100)	N=36 84.26 100 (0-100)	N=36 88.89 100 (0-100)
RE Subject SH Mean Median (Range)	N=64 77.08 100 (0-100)	N=64 78.65 100 (0-100)	N=34 84.31 100 (0-100)	N=34 72.55 100 (0-100)	N=34 81.37 100 (0-100)
MH Subject TS Mean Median (Range)	N=92 68.24 72 (0-100)	N=92 75.65 76 (28-100) •	N=70 72.11 76 (16-100)	N=70 74.44 76 (12-100)	N=70 76 80 (8-100) *1
MH Subject FH Mean Median (Range)	N=27 67.78 76 (0-92	N=27 77.19 80 (48-100) *	N=36 71.78 76 (16-100)	N=36 78.53 82 (16-100) *	N=36 81 88 (28-100) •1
MH Subject SH Mean Median (Range)	N=59 68.54 68 (0-100)	N=59 74.24 76 (28-96) *	N=28 74 76 (32-92)	N=28 71.14 74 (40-88)	N=28 72.29 72 (8-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

For those in the family homes no significant difference was found between the two groups at the outset (median = 100, for both). For the Group A participants, an increase occurred which was reflected in the mean score (Pre = 77.08, Post = 90.63) and this was found to be significant at the level of $p<0.045$. Those in Group B showed no significant change over time and the two family home groups were not found to differ significantly at any of the time points.

At the outset, no significant difference was detected between the two staffed home groups (median = 100, for both). For those in both groups, there was little change over time and no significant within group changes, or between group differences were found.

Mental Health (MH)

The baseline scores for the subjects' mental health were compared (Table 22) and no statistical differences were found between the two groups (medians 72 and 76, respectively). An increase occurred in Group A that reached the significance level of $p<0.001$, while in Group B, stability was maintained between Pre 1 and Pre 2. In Group B at Post, the scores increased resulting in a significant change with Pre 1 ($p<0.019$), but not with Pre 2. This would suggest an upward trend rather than an intervention effect. At no time point were the two groups found to differ significantly.

For those in the family homes, no significant differences were found between the two groups at the outset (median = 76, for both). For those in Group A, there was a significant increase at Post ($p<0.029$), with a similar increase for Group B participants ($p<0.018$) between Pre 1 and Pre 2, suggesting instability in the scores. At Post, for those in Group B, the scores increased, resulting in a significant change between Pre 1 and Post ($p<0.001$), but not Pre 2. No between group differences were identified between the family home groups at any of the time points.

The participants in the staffed homes had similar scores for mental health at baseline and no significant differences were detected between the two groups (medians 68 and 76, respectively). Those in Group A increased in score at Post, which achieved a significance level of $p<0.033$. Little change occurred over time for those in Group B and no statistically significant changes were identified. No significant differences were found between the staffed home groups at any of the time points.

3.4 Analysis by Patient Characteristics

In order to investigate whether particular characteristics of the subjects influenced the impact of the intervention, further analyses were undertaken. The subjects were divided into sub-groupings according to the presence or absence of the triad of social impairment, challenging behaviour and mental illness, and the results were then examined separately for each of these groups (Full data is given in Appendices 19-24). Further analysis was also undertaken on whether the subject had one, or more health needs identified during the health check and if all, some or none of the individual's health needs were treated.

3.4.1 Subjects with and without the triad of social impairment and their carers

Subjects with the triad of social impairment and their carers

There were 72 patients in total in the study with the triad of social impairment, 41 in Group A and 31 in Group B. There was no evidence to suggest that the presence of social impairment had any impact on the effectiveness of the intervention. Only three significant differences were found at baseline between the two groups, with those in Group A showing higher levels of activity in the community (Index of Community Involvement, $p<0.010$ and Index of

Community Involvement Frequency, p<0.036), and lower scores on the General Health subscale (SF-36, p<0.043). The Group B participants showed no significant changes over time and those in Group A showed a decrease at post intervention in levels of choice (Choice, p<0.038), in general physical activity (Diary A, p<0.0001) and in energetic activity (Diary B, p<0.020), while improvements were detected in perceived vitality of the subject (p<0.015) and mental health (p<0.018).

Similarly, no pattern of change was evident in carer stress and perceived health. For the carers of individuals with the triad, no differences were found between the two groups at the outset, and for the carers in Group A, only one significant change was noted: an increase in the level of intensity of emotional exhaustion (Maslach, p<0.042). As some of the staffed home carers were responsible for more than one subject, there were only four of them in Group B, and therefore it was not possible to conduct any further within group analysis on the Maslach.

Subjects without the triad of social impairment and their carers

For those without the triad of social impairment, there were 65 subjects in Group A and 50 in Group B. The results did not indicate any evidence that the absence of the triad of social impairment had any impact on the effect of the intervention. Individuals without the triad were not found to be significantly different on any of the measures at the outset when the two groups were compared. Subjects in Group A showed some significant changes with decreases in indications of mental illness (PIMRA, p<0.020), energetic physical activity (Diary B, p<0.0001) and in the individual's level of choice (Choice, p<0.004). For subjects in Group A, the only significant change was an improvement on the mental health subscale (SF-36, p<0.014). Those in Group B showed a significant increase in ABS score at Post with Pre 1

($p<0.0001$) and Pre 2 ($p<0.0001$) with both changes reaching the Bonferroni level of significance.

For the carers, too, no intervention impact was evident. At the outset, the two carer groups were different only in terms of mental health, with those in Group A showing more positive mental health scores compared to those in Group B ($p<0.049$). The carers in Group A showed a significant increase in the level of intensity of emotional exhaustion (Maslach, $p<0.028$) and a decrease in score on the Role Emotional subscale (SF-36, $p<0.018$). Those in Group B showed a significant decrease in carer stress shown by changes between Pre 1 ($p<0.010$) and Pre 2 ($p<0.032$) with Post on the Caregiver Strain Index. There was no data available from the staffed carers in Group B for the Maslach Inventory.

3.4.2 Subjects with and without challenging behaviour and their carers

Subjects with challenging behaviour and their carers

Subjects with challenging behaviour were identified using the irritability and hyperactivity subscales within the Aberrant Behavior Checklist (Aman & Singh, 1986). If a subject obtained a score of 3 (highest level of severity) on five or more items or had a total score of 31 or more on the two subscales, they were deemed to have challenging behaviour, in accordance with the criteria employed by Lowe, Felce, & Blackman (1995).

Thirty-one individuals were identified as having challenging behaviour, 17 in Group A and 14 in Group B. Only the level of individual choice (Choice), in both groups showed a deterioration at post intervention. The two groups of individuals with challenging behaviour differed only slightly at the outset, with those in Group B showing higher levels of energetic activity (p<0.047) and lower scores on the Role Emotional subscale (SF-36, p<0.007). Significant decreases occurred for those in Group A at Post for the total score of challenging behaviour (ABC Tot, p<0.022), levels of choice (Choice, p<0.042) and levels of energetic activity (Diary A, p<0.021). The Group B subjects showed a significant decrease in level of choice at Post compared with Pre 1 (Choice, p<0.018) and Pre 2 (Choice, p<0.017) and an increase at Post between Pre 1 (p<0.016) and Pre 2 (p<0.037) in terms of physical functioning (SF-36). A between group difference was also found between Group A Pre and Group B Pre 2 for level of choice (Choice, p<0.005), with those in Group A showing lower scores compared to those in Group B, which concurred with the deterioration indicated in the two groups at Post. For the carers of individuals with challenging behaviour no significant differences were detected between the groups and no significant within group changes were found throughout.

Subjects without challenging behaviour and their carers

There were 154 subjects without challenging behaviour in the study, 88 in Group A and 66 in Group B. Overall, no pattern of change was identified for subjects without challenging behaviour to indicate any measurable impact of the intervention. Only one significant difference was identified at the outset between the two subject groups, with the Group B subjects showing higher levels of emotional health than those in Group A (Role Emotional subscale, p<0.007). As for those with challenging behaviour, subjects in Group A showed a significant decrease at Post for level of choice (Choice, p<0.005). Subjects in Group A also showed a significant decrease at Post for general activity (Diary A, p<0.004) and energetic activity (Diary B, p<0.0001), with the later reaching the Bonferroni Test level. A significant positive increase was also found for those in Group A, for emotional health (Role Emotional subscale p<0.045) and mental health (Mental Health subscale p<0.012) on the SF-36. For those in Group B, the Index of Participation in Domestic Life showed an increase at Post with Pre 1 ($p<0.017$) and with Pre 2 ($p<0.047$) and a similar increase on the Physical Functioning subscale (SF-36, Pre 1, $p<0.016$, Pre 2, $p<0.037$). The ABS also showed an increase at Post, with Pre 1 ($p<0.0001$) and Pre 2 ($p<0.001$), the former which reached the significance level of the Bonferroni Test. However, no significant changes were noted for those in Group A on any of these measures.

A possible intervention effect was indicated by a decrease in the stress levels of the carers in both groups at Post. At the outset, none of the measures showed a significant difference between the two groups of carers of individuals without challenging behaviour. For those in Group A, a significant decrease was shown in carer stress (Carer Index, $p<0.025$) and a significant increase in intensity of emotional exhaustion (Maslach, $p<0.012$) was identified. For subjects in Group B, only the Carer Index showed a significant change, which was a decrease between Pre 1 ($p<0.007$), Pre 2 ($p<0.044$) and Post. However, a significant difference occurred between the two groups at Post ($p<0.024$) rather than between Group A at Post and Group B at Pre 2, which might suggest that a gradual change was occurring over time, rather than any intervention effect.

3.4.3 Subjects with and without an indication of mental illness and their carers

Subjects with an indication of mental illness and their carers

Eighty two individuals were found to have indications of mental illness: 43 individuals in Group A and 39 in Group B. Subjects with an indication of mental illness were identified using the Psychopathology Inventory for Mentally Retarded Adults (Matson, 1988). As suggested by the author, if four symptoms on any of the subscales were present, this was taken as an indication of a mental illness.

There was no evidence to indicate that the presence of mental illness had any influence on the impact of the intervention on subjects or their carers. At the outset, the individuals in Group B were mentally healthier than those in Group A (Mental Health subscale SF-36, $p<0.034$). For those in Group A an improvement occurred at Post for mental health (PIMRA, $p<0.004$), and on the following subscales: Bodily Pain (SF-36, $p<0.018$), Vitality (SF-36, $p<0.033$) and Mental Health (SF-36, $p<0.001$). The scores for those in Group A were found to decrease significantly at Post in levels of general activity (Diary A, $p<0.003$) and energetic activity (Diary B, $p<0.027$). The subjects in Group B showed an increase in ABS score at Post both with Pre 1 ($p<0.003$) and with Pre 2 ($p<0.006$), but no changes were found for subjects in Group A on this measure.

The carers of individuals with an indication of mental illness showed no differences between the groups at baseline. The carers in Group A showed a significant increase at Post for Emotional Exhaustion Intensity (Maslach, $p<0.043$) and a decrease at Post on the Social Functioning subscale (SF-36, $p<0.026$). No significant changes that followed the experimental design were detected for those in Group B.

Subjects without an indication of mental illness and their carers

There was no indication in the results that the absence of mental illness had any measurable impact on the effectiveness of the intervention. For individuals who had no indication of mental illness at baseline, no significant differences were detected between the two groups. The subjects in Group A showed a significant decrease at Post for level of choice (Choice, p<0.0002), level of energetic activity (Diary A, p<0.047) and general activity (Diary B, p<0.0001), with the latter reaching the Bonferroni significance level. For subjects in Group B there was a significant increase in ABS scores at Post with both Pre 1 (p<0.003) and Pre 2 (p<0.006).

Little change was evident for the carers of individuals without a mental illness, to indicate any impact of the intervention. At baseline there were no significant differences between the two groups of carers. The carers in Group A showed a decrease at Post for carer stress (Carer Index, p<0.048), and an increase for Emotional Exhaustion Intensity (Maslach, p<0.043) and Personal Accomplishment Intensity (Maslach, p<0.043). For the carers in Group B, a significant change was identified on the Role Physical subscale (SF-36), which indicated a decrease at Post with Pre 1 (p<0.043) and Pre 2 (p<0.026). A significant increase at Post was also detected on the Social Functioning subscale (SF-36) with Pre 1 (p<0.023) and Pre 2 (p<0.005).

3.5 Analysis by Health Need Identified

In order to investigate whether the identification of one or more health needs and whether these were treated or not had an impact on the intervention effect, the data were reanalysed in subgroups according to these outcomes (Full data is given in Appendices 25-29).

3.5.1 Impact on those who had one or more and those who had no health needs identified and their carers

Those who had no health needs identified and their carers

There was no evidence to suggest that not having a health need identified had any measurable impact on the intervention effect. At the outset, those in Group A were shown to have a lower indication of mental illness (PIMRA, p<0.032) and less involvement in community activity than those in Group B, but no significant differences were found in any other respect. For subjects in Group A, a significant decrease was found at Post for level of energetic activity (Diary A, p<0.025) and general activity (Diary B, p<0.001). A significant increase was indicated for subjects in Group B on the ABS at Post with Pre 1 (p<0.0001) and Pre 2 (p<0.0001), with both reaching the Bonferroni Test level of significance. In addition, those in Group B showed an increase on the Vitality subscale (SF-36) at Post with Pre 1(p<0.029) and Pre 2 (p<0.044).

For the carers, there was no evidence to suggest that the individual not having a health need identified, had any influence on the results. Those in Group B showed higher levels of physical ability at baseline than those in Group A (Role physical subscale, SF-36, p<0.006). For the Group A carers, the only measure to indicate a change was the Carer Index which showed a decrease at Post in the stress levels of the carers at the level of p<0.014. No significant changes were identified for those in Group B.

Those who had one or more health needs identified

There was some suggestion of a possible intervention effect for those who had health needs identified as their level of general physical activity was indicated to decrease at post intervention. At the outset, the only difference detected between the two groups was that the subjects in Group A were found to have significantly lower scores on the Role Emotional subscale (SF-36, p<0.047). For subjects in Group A, significant decreases were identified at Post for level of choice (Choice, p<0.002), level of energetic activity (Diary A, p<0.008) and general level of activity (Diary B, p<0.001), as well as a positive increase detected in mental health (Mental Health subscale, SF-36, p<0.003). For those in Group B, a significant decrease was shown on the Physical Functioning subscale at Post with Pre 1 (p<0.001) and Pre 2 (p<0.0001), with the latter reaching the Bonferroni Test level of significance. In addition, a decrease in general level of physical activity occurred for those in Group B at Post, with Pre 1 (p<0.002) and Pre 2 (p<0.048). These changes in level of general physical activity for the subjects in Group B corresponded with the change at Post for subjects in Group A, but no significant between group difference was indicated at Pre 2. These changes may indicate more of a downward trend for subjects in Group B, but could also suggest a possible effect of the intervention.

For the carers of individuals with a health need identified, significant differences were found at baseline, with those in Group A showing a greater state of general health (General Health subscale, p<0.009) and mental health (Mental Health subscale, p<0.022). Significant changes were found only for those in Group A, with an increase in Emotional Exhaustion Intensity (Maslach, p<0.008), and a decrease in vitality (Vitality subscale, p<0.032).

3.3.2 Impact on those who had health needs treated

Approximately 63% of the patients in both groups had one health need and a quarter of the patients had two health needs identified during the health check (Table 24). Overall, 12% of patients had more than two health needs identified, three subjects in each group had three health needs identified and a further 5 subjects in Group A had 4-5 health needs discovered during the health check.

Table 29. The number of health needs identified during the health check by group

	Group A N=58	Group B N=35	Total N=93
One health need identified	36 (62.1%)	23 (65.7%)	59 (63.4%)
Two health needs identified	14 (24.1%)	9 (25.7%)	23 (24.7%)
Three health needs identified	3 (5.2%)	3 (8.6%)	6 (6.5%)
Four health needs identified	1 (1.7%)	-	1 (1.1%)
Five health needs identified	4 (6.9%)	-	4 (4.3%)

The identified health needs had not, in all cases, been treated at the point of the audit interview. In some instances, the treatment was in progress and, in some cases the patient or carer had refused treatment. The majority of patients had all their health needs treated by the time of audit, but approximately a third of patients in both groups had health needs that remained untreated or in progress at the time of the audit (Table 25). Therefore, further analysis was conducted to explore any differences between patients who had received treatment for all their health needs (Treated), some of their health needs (Partly) or none of their health needs (Untreated). The data are presented both for the subjects and their carers in the separate groupings (Full data is given in Appendices 27-29).

Table 30. The number of health needs that had been treated at the time of the audit

	Group A N=58	Group B N=35	Total N=93
All health needs treated (Treated)	23 (39.7%)	18 (51.4%)	41 (44.1%)
Some health needs treated (Partly)	13 (22.4%)	6 (17.2%)	19 (20.4%)
No health needs treated (Untreated)	22 (37.9%)	11 (31.4%)	33 (35.5%)

Subjects who had all identified health needs treated (Treated)

Of the subjects who had health needs identified, 41 individuals had all their health needs treated: 23 in Group A and 18 in Group B. Overall, for these subjects there was some indication of a slight effect of the intervention, with a decrease in activity levels detected across both subject groups. At the outset, the only difference between the two groups was that those in Group A showed lower scores on the Role Emotional subscale (SF-36, $p<0.031$). The subjects in Group A at Post showed decreases in indications of mental illness (PIMRA, $p<0.045$) and general activity (Diary B, $p<0.045$), and a positive increase in mental health (Mental Health subscale SF-36, $p<0.013$). A significant decrease was found for the Group B subjects in general activity at Post with Pre 1 ($p<0.003$) and Pre 2 ($p<0.023$) suggesting a possible effect of the intervention, but without a between group difference between Group A at Post and Group B at Pre 2, the results could also be indicating a downward trend over time. The carers of subjects who had all of their health needs treated showed no between group differences at baseline, and no significant changes throughout.

Subjects who had some identified health needs treated (Partly)

There were 19 subjects in total who had only some of their health needs treated, 13 of these were in Group A and 6 in Group B. The results did not indicate any pattern of change to suggest that having some health needs treated had any influence on the effect of the intervention. At baseline, the only differences between the two groups were shown on the Vitality and Mental Health subscales of the SF-36, with the subjects in Group B reporting higher energy levels (p<0.022) and more positive mental health (p<0.030). For the subjects in Group A, only one significant change was identified, which was an increase on the Vitality subscale (p<0.024). For the subjects in Group B, no significant changes were indicated over time. For the carers of subjects who had some of their health needs treated, the two groups were found to be significantly different on the Role Physical (p<0.017) and Role Emotional (p<0.008) subscales, with the carers in Group B reporting greater limitation in their activities due to their physical and emotional health. No within group changes were found on any of the other measures, although, again, it was not possible to perform any analysis on the Maslach, as there were no carers from the staffed homes in Group B.

Subjects who had none of their identified health needs treated (Untreated)

Thirty-three subjects who had none of their health needs treated: 22 in Group A and 11 in Group B. There was no indication to suggest that having none of the identified health needs treated had any impact on the intervention effect. At the outset, the two groups differed only on the ICI (p<0.016), with the subjects in Group B having a significantly higher level of involvement in the community at baseline, when compared to the subjects in Group A. For the Group A subjects, significant decreases were identified at Post in levels of choice (Choice, p<0.007), energetic physical activity (Diary A, p<0.045) and general activity (Diary B, p<0.030). For subjects in Group B, a significant decrease was shown on the Physical Functioning subscale at Post, compared with Pre 1 (p<0.036) and Pre 2 (p<0.038). The carers of subjects who had none of their health needs treated differed at baseline only in the level of malaise reported, with those in Group A showing significantly higher scores at baseline than those in Group B ($p<0.048$). The carers in Group A showed a significant increase at Post for Emotional Exhaustion (Maslach, $p<0.028$) and a significant decrease at Post on the Vitality subscale ($p<0.026$). There were no significant changes detected for those in Group B.

4.0 Discussion

This study has focused on a primary care identified population of individuals with a learning disability, with an aim to explore the effect of a health check on their quality of life, and on their perceived health and that of their carers.

The study was conducted over approximately a three-year period, involving 40 general practices and 190 adults with a learning disability and their carers. The subjects were divided into two groups according to practice; an experimental group (Group A) and control group (Group B). Baseline data were collected once for the experimental group and twice for the control group, with an interval of 6 months to control for extraneous variables. An intervention was then introduced in both groups through the primary care team. This consisted of: the administration of the Cardiff Health Check, an Education Package and an Audit Interview. Post intervention data were collected on all subjects and carers, four months on average, after the administration of the Health Check.

To explore whether having a health check had any effect on the quality of life or perceived health status of the individual, subjects' ability, behaviour, mental health, level of community activity, level of choice, level of physical activity, carer perceived degree of epilepsy and perceived health status were examined, for any changes occurring as a result of the intervention. Also, to investigate whether the intervention had any measurable effect on the stress levels or perceived health of the carer, the level of malaise for carers in family homes, the level of 'burnout' of staff in residential homes and the perceived health status for all carers were examined for any changes that could be attributed to the intervention. In order to investigate whether the characteristics of the subject may have had any effect on the impact of the intervention, the data were reanalysed in sub groupings to examine any possible influence of social impairment, challenging behaviour and mental illness. Further analyses were also undertaken to explore any differential impact of having one or more health needs identified and the effect of whether these were treated, partly treated or not treated.

4.1 Main Findings

For the health checks to show an impact on quality of life, one would expect to see: no significant differences between the two groups at baseline, a significant change at post for the experimental group, stability between the baseline data collections for the control group, followed by a change at post similar to that of the experimental group. Also, if this were accompanied by a significant difference between the experimental group at post and the control group at the second baseline data collection, this would give an additional indication that any change was due to the intervention.

The results indicated that comparability between groups was largely achieved, with only a few differences detected between the groups, for the residential groupings and on some of the sub groupings. Overall, mostly random changes occurred with only a few patterns of change emerging over time. Across the whole sample, the family home subjects showed lower levels of general activity at post intervention, and their carers had lower levels of stress. Patients with challenging behaviour showed a decrease in level of choice at post intervention and the carers of those without challenging behaviour reported a reduction in stress levels. A deterioration in general activity was found for those who had health needs identified and for those who subsequently received treatment.

The two clearest results appeared to be the reduction in the level of choice for those with challenging behaviour and the deterioration in activity for subjects from family homes. For these findings, there was also a significant difference between the groups when the post scores for the experimental group were compared with the second baseline scores of the control group and thus the full experimental design was achieved. However, the reduction in the level of choice could not be attributed to the presence of challenging behaviour, as a similar reduction was also noted in the experimental group for those without challenging behaviour. Moreover, a significant reduction of activity was noted in the experimental group for the staffed home subjects, which suggested that a deterioration in activity was not only occurring for subjects in the family homes. Similarly, decreases were also noted for several of the subgroups. Indeed, visual inspection of the data indicated a general decreasing trend over time, which would suggest that any changes were artefactual rather than due to any intervention effect.

These findings do suggest that health checks had a limited impact on the quality of life of the individual and the carer as measured in this study. The study, however, yielded a large amount of information on the health needs of individuals with a learning disability and how these are currently addressed within primary care. The study and the implications of the results are now discussed.

4.2 Attenuation of Sample

Before discussing the study findings, it is important to address the attenuation in the sample, which was far greater than expected. There are two possible explanations for this, firstly the inherent difficulties of implementing health checks within primary care, and, secondly the amount of data collected on each subject, which may have deterred carers from further participation.

Clearly, there were some obstacles to all the subjects receiving the health checks as planned. Fifty-two subjects did not receive a health check: half of these did not receive a health check during the study period, a quarter were not given one by the practice and the remainder refused or did not attend the appointment. There was considerable variation between the primary care teams in terms of the length of time taken to administer the health checks. It was anticipated that practices would take three to six months to complete the health checks but, in some instances, the practices took almost a year. In line with the staggered design, the practices came onto the study over the period of one year, which allowed all practices at least six months to administer the health checks. However, if the practices coming later onto the study took longer than six months, then the health checks were not completed within the study period. The practices were contacted by telephone at regular intervals and the impression gained that workload was the main reason for delay. In the instances when the practices had not conducted the health checks at all, it is possible that the patients had refused or not attended the appointments, but neither this nor other reasons were reported by the practices at the time.

The second possible explanation for the attenuation from the study was the time taken for data collection. Generally the data collection took two hours for each subject, which sometimes required a second visit. Baseline data collection took slightly longer as the Disability Assessment Schedule was also included. In the staffed homes, the additional information on the residential setting and the staff team could double the time taken for the baseline data collection. In addition, subjects in the control group had a second baseline data collection before the health check was conducted. Thus, the total time contributed by the carers for data collection could have been as much as six hours for those in the family homes and eight hours for the staffed home carers. Also, for carers in staffed homes, there were instances where a member of staff was a key worker for more than one individual participating in the study and thus was required for multiple interviews. In hindsight, the use of fewer measures may have been preferable, in order to reduce the risk of individuals leaving the study.

However, considering the time taken for the data collection conducted in the staffed homes, it was surprising to find that 28% of the individuals from staffed homes left the study compared to 48% from family homes. A possible reason is that the staffed home carers were giving paid work time to the study, whereas the family carers would have been giving personal time, in addition to caring for the individual. It is also conceivable that within the staffed homes, although the key worker may have wished to withdraw, the decision to remain in the study was made by the manager of the home.

Nonetheless, it was not expected that individuals would chose to withdraw from the study during the final data collection when so much time had already been invested. Two impressions were gained from the carers: some showed a lack of interest in the study and others reported disappointment with the health checks. Possibly due to data collection being conducted over a two-year period, some carers did seem to lose interest towards the end of the study and, once the health check had been conducted, there was perhaps less motivation to continue. Some carers appeared disappointed with the health checks, when they felt they had not being given enough time with the doctor: some due to a short appointment and others where the health check had been conducted by the nurse.

Despite the attenuation, the study still successfully obtained full data sets for one quarter of the recorded practice population of adults with a learning disability, based on estimates taken from social services registers. It was calculated that 745 adults were estimated as originally identified by the practices, half of these consented initially to be contacted by the research team and a quarter fully participated for the duration of the study. Indeed, the forty practices in the study represented 12% of the total number of practices across the three health authorities, and covered a patient population of 353,602 individuals, representing a fifth of the total 1805,065 patient population in the three health authorities.

4.3 Representativeness of the Sample

Given the attenuation in the sample, the representativeness of the final sample needs to be considered. The characteristics of the subjects were generally similar between the initial and final samples, and no significant differences were found in terms of ability, level of behaviour problem, gender, age or presence of mental illness. The Adaptive Behaviour Scale scores were examined for the initial and final samples to see if either was skewed at either end of the normal distribution but this was found not to be the case, and the subjects' range of ability was spread equally across the total final sample, and also when divided by practice into the experimental and control groups.

There was, however, a statistically significant higher number of individuals with the triad of social impairment remaining in the study, which suggested that carers of individuals with particular problems were more likely to continue participating, perhaps in the hope of receiving additional help from the primary care team. A limitation of this study is that the patients who agreed to participate were self-selecting, and it was not possible to collect any data on those who did not agree to participate. The primary care teams were asked to re-contact those who had not responded but it is possible that in the staffed homes, the request to participate forms may not have reached the correct person to give consent. It is also a consideration that individuals who had a particularly good relationship with their GP would be more likely to participate than those who did not. Also, carers who were concerned about the individual's health needs may have been more likely to take part, and as well as those with an interest in research being conducted for people with a learning disability. However, a particular interest in the research topic is likely to be a characteristic of any voluntary participants.

On the whole, the characteristics of the carers too, were similar in the initial and final samples. The carers were not found to be different in terms of level of 'burnout' stress or strain but some differences were found on the subscales of the SF-36, indicating that the carers who left the study were less physically able, suffered from more bodily pain and were less able to do activities due to emotional difficulties. As mentioned earlier, there was found to be a difference in the residence of the subjects, with a greater proportion of staffed home residents in the final sample compared to the initial sample, which would suggest the possibility that more family carers than paid carers found the volume of data collection unacceptable.

In many respects the final sample was similar to that found in other studies. In terms of ability, the average Adaptive Behaviour Scale score of 166.9 was similar to the level reported by Lowe & de Paiva (1991), of 164.54 for people living in the community in staffed and family homes. Also, the percentage of individuals with challenging behaviour of 16% was comparable to other findings of 17% (Qureshi & Alborz, 1992) and between 10-15%

(Emerson et al., 2001). The average age of participants on the study was 42 years which was slightly higher than found by Smith et al. (1996), of 37.7 years and by Lowe & de Paiva (1991), of 37 years in their total population studies.

Other studies have found variability in levels of mental illness, for example Deb et al., (2001) found that 16% of their sample had mental illness, which is considerable lower than that found by Cooper, (1997) of 47.9%. The current study identified 43.4% using the criteria of the Psychopathology Inventory for Mentally Retarded Adults (PIMRA). However, it must be noted that the actual percentage of patients with a mental illness in the current study may have been slightly lower, as the PIMRA measures indications of mental illness but, without a psychiatric assessment, is not a diagnosis.

Other studies have found a higher percentage of males than females (Lowe & de Paiva, 1991; Evans et al., 1994; McGrother et al., 1996) and this would normally be expected (McLaren & Bryson, 1987). However, in the current study, in both the initial and final samples a higher percentage of females was found. The reasons for this are unclear, it is possible that the primary care teams were more likely to identify females in the learning disabled population, who are more likely to pay regular visits to the general practice surgery for gynaecological issues or that the carers of female patients were more likely to agree to participate. As no data are available on the gender of those refusing to consent, it is not possible to investigate this further. However, the level of carer concern about individuals' health and whether this is affected by certain patient characteristics may be an area for future research.

Other studies have shown that just under half of subjects live in staffed homes (Smith et al., 1996; McGrother et al., 1996), which suggests that the initial sample may have been more representative, with the tendency for those in family homes to withdraw causing an over representation of individuals in staffed homes in the final sample. In the current study, the presence of the triad of social impairments was evident for over a third of the sample. Other studies have found a lower prevalence of individuals with the triad in staffed homes at 21% (Felce & Perry, 1995a) and 23% (Perry & Felce, 2002), suggesting that a slightly higher percentage of individuals with the triad were recruited onto the current study than would have normally be expected. This may suggest that carers of those with severe disabilities were more willing to participate. Again, without data on those who did not participate, it is not possible to draw any firm conclusions.

In relation to the practices that participated on the study, their characteristics were found to be generally similar to that of their respective health authorities as a whole. In terms of deprivation, the study practices from both Dyfed Powys and Gwent showed levels of just below zero, which were almost identical to the deprivation levels of their respective health authorities. The average score for the study practices in Bro Taf of 5.12 was higher than that for the health authority overall of 1.8, although the wide score range among the study practices, from -7.50 to 24.9, suggests considerable variability in deprivation across the health authority as a whole.

The average size of the study practices was slightly larger than the average size across the health authorities as a whole. This was possibly because the greater resources made available by a bigger staff team, allowed more flexibility for staff to take on additional commitments. However, two single practitioner practices participated, which was unexpected due to the additional time pressures on a GP working alone in a practice. An explanation as to why these two single GP practices took part may be that they had a special interest in patients with learning disabilities, or because there were a high number of learning disabled individuals on their practice registers. As one of these single GP practices was located close to the previous site of a long stay learning disability hospital, it is possible that this had generated an interest for this particular primary care team, who may have been concerned about the responsibility of additional patients with learning disabilities joining the practice. Current research on the attitudes of nurses, therapists (McConkey & Truesdale, 2000) and GP's (Gill et al., 2002) has suggested that frequent professional contact with individuals with learning disabilities may be associated with more positive attitudes and it is possible that an increase in the number of such patients may have positively influenced this practice.

However, practices may have chosen to participate for reasons other than a concern for the health care of learning disabled individuals. The educational element is another consideration, as the education package used in the study was recognised as further training for GP's. Those who took part were awarded PGEA points (training points for GP's), of which GPs are encouraged to acquire a certain number each year. This may have resulted in some GPs wishing to participate due to an interest in further training but who did not necessarily have a special interest in people with learning disabilities. However, it is also possible that some practices may have been concerned that they were now responsible for this population of people and felt that the additional education provided by the study would be of benefit.

4.4 Possible Factors Influencing the Impact of the Intervention

The limited impact of the intervention was disappointing. There are several possible explanations as to why the intervention was found to have so little impact on the quality of life of the subjects and carers. Firstly, it has to be considered that health checks per se may, indeed, not have any impact on quality of life. However, another explanation could be that the measures were insufficiently sensitive to identify changes in individuals and carers. Alternatively, subjects and carers may have had a variable response to whether a health need was identified and subsequently treated. Finally, the impact of the intervention on patients and carers may have been influenced by the variation in how the health checks were conducted within the primary care practices.

Quality of life measures have been advocated by a number of researchers to measure the benefits of health checks and have been found to be reliable in other populations of individuals with a learning disability and their carers. The benefit of health checks to the individual in terms of improved quality of life was highlighted by Martin & Roy (1999) as an area for further research, and the multidimensional model of quality of life put forward by Felce & Perry (1995b) suggested that an improvement in an individual's physical health may influence other areas of wellbeing. Also, a more recent study indicating an association between health status and behavioural disorder in people with learning disabilities, has suggested that behaviour disorder may be an indicator of undetected health needs (Davidson et al., 2003).

The scales selected for this study have been frequently used in various other studies to measure different aspects of quality of life. For example, the Adaptive Behavior Scale has been used extensively to measure development and activity (e.g. Felce et al., 1986), and the Index of Community involvement to measure social well-being (Raynes al al., 1994). The SF-36 has been widely used as a measure of health for the general population (Ware, 1993), and the proxy version of the scale had been used with other groups of patients (Wagner et al, 1996). Also, for carer stress and strain, the Malaise Inventory (Rutter, 1970b; Sloper et al., 1991) and the Caregiver Strain Index (Thornton & Travis, 2003) are also widely used measures. Based on the evidence of the use of these measures, it was anticipated that any impact from the intervention would be detected. However, although established measures were used, it is possible that these were still insufficiently sensitive to pick up small or subtle changes in subjective experience. Another consideration is that the time period allowed between the health check and the post data collection may not have been long enough to allow for much measurable change to have manifested.

For instance, if an individual had their ears syringed as a result of the health check, the effect on the individual could be dramatic if their hearing was subsequently restored. If the ability level of the individual were measured using the Adaptive Behavior Scale, any changes would likely be noted in the Language Development domain of the scale. Although such a dramatic change may have a noticeable effect on the score for the individual in this domain, the other domain areas would probably remain at the same level and, therefore, the changes in the scale as a whole may not noticeable. Similarly, for behaviour as measured by the Aberrant Behavior Checklist, a change in behaviour may reduce the irritability of the individual, due to the treatment of, for example, a skin condition. However, this change may not show in the other four areas of behaviour of lethargy, stereotypy, hyperactivity and inappropriate speech and, therefore, may not have sufficient impact on the overall scores of the scale to indicate a change. More subtle measures may be required, with direct, individualised questions, to measure any specific changes anticipated by a change in health status.

The time period between the intervention and the data collection may also have been a factor due to the time taken in many instances for treatment to occur and possibly take effect.

Although a minimum of two months was generally allowed before post data collection commenced, in some cases, a follow-up appointment with the nurse for ear syringing, for example, could take several weeks. Thus, the scales could have been administered as the treatment was happening, rather than after it had occurred. In addition, changes in quality of life as a result of the treatment of a health need may not happen instantly. The example of an improvement in hearing due to ear syringing may not have any impact on the individual's language and understanding for some time, as their learning abilities may need time to develop. Thus, it could be that the repeated measurement of the individual's quality of life over time is needed in order to show the full impact of such a change in health.

For the purposes of analysis, the health needs were grouped together to try to ascertain any effect of the health check process, but how an individual may react to a change in health status is difficult to predict as, by its very nature, it is likely to affect each person in a different way. Even the process of the health check may have been a positive experience for some individuals who may have enjoyed the additional attention from the health professional whereas, for others, it may have been distressing. When the subjects were measured as a whole group, the positive experiences of some and the negative experiences of others may have resulted in a midpoint of change, which would show little impact from the intervention. Across the sample, a range of health needs and a range of different treatments were identified, some which may have had more of an impact on the individual than others. For example, subjects who had the thyroid function test would have received a blood test which, unless it was found to be positive for hypothyroidism, is unlikely to have impacted on the individual any further. In contrast, subjects having their ears syringed may have subsequently benefited from improved hearing and, thus, the change may have resulted in a health improvement, although not all individuals may have instantly noticed a change in hearing or benefited from any immediate change in quality of life indicators.

Future research of the effect on quality of life of health checks may need to take account of the complexity and variation in response, to a health intervention. The reanalysis of whether the health needs, once identified, were subsequently treated, did attempt to further divide the group of individuals who had a health need identified into whether a health improvement had occurred or not. However, the attempt to account for the different outcomes reduced the group size, making it difficult to measure any change statistically.

Similarly, the health check is likely to affect carers in different ways. It has been highlighted that carers are often affected by the health status of the individual but how carers react to a change in the person's health may differ. As previously discussed, differences could be expected between the staffed and family carers, due to the care demands placed on one or two family carers compared to a full staff team. Likewise, the degree of emotional attachment between the paid staff carer and the family member is different and is likely to be reflected in the degree of stress and strain experienced due to the individual's state of health. This difference between the two groups of carers was accounted for to some degree by the analysis by residence but the different reactions to the health check process and identification of a health need was not. Some carers may well have found the health check process reassuring in that the primary care team were paying attention to the individual's health and this may have been greater for the family home carers who may have been more affected by this. However, other carers may have found the process quite distressing, particularly if the process upset the patient. Likewise, with respect to the identification of a health need, this may have been a relief to some carers if they had suspected something wrong with the individual but, to others, the knowledge of a previously unidentified illness that may need further treatment or referral appointments may have increased their stress. These variations in the carers as a group could have resulted in changes balancing out in the data to produce results showing little overall impact of the intervention.

Nonetheless, despite the higher levels of stress and strain found in the family home participants, decreases were shown in carer strain at post intervention for carers in family homes and carers of those without challenging behaviour. However, carers of those without challenging behaviour represented 97 % of family carers in the experimental group and 87% in the control group and, therefore, the same pattern of results could be expected. The decrease in level of strain for those in family homes was indicated by the changes in each group over time, but was not accompanied by a significant difference between the experimental group at post and the control group at the second baseline data collection. Instead, a significant difference was found between the two groups at post suggesting that the degree of change was not the same in both groups. The small score range on the scale may have exaggerated the differences between the groups and, indeed, the degree of change at post intervention, however, the findings do suggest a pattern that is worth considering as a possible outcome of the health checks, and an area for further investigation.

It is feasible that the family carers may have felt a certain benefit from the health checks being conducted, considering the findings in the literature that the individual's health is of particular concern to family carers (Conroy, 1985; Harris & McHale, 1989). In re-examining the results for those who had a health need identified and those who did not, the former showed a pattern of results that almost followed the experimental design, with the comparison between Pre 2 and Post for the control group just missing the significance level

($p<0.055$). It could be tentatively suggested that the person with a learning disability having received a health check provided some reassurance for carers that the individual's health was being attended to. This would agree with the work of Conroy (1985), that highlighted family members' concern with the level of medical attention the individual required. As the experimental design was not achieved for those who had no health needs identified, no conclusions can be formed, but the overall findings from the current study may indicate an area for future research in exploring family carers' concern regarding the health status of the individual with a learning disability. The fact that no changes were detected on the SF-36 for the subject suggests that the effect was not that carers believed the individual to be in better health after the intervention, but that the process of the health check reassured them.

Overall, the results suggest that, in terms of strain and malaise, the family carers were experiencing above average levels of stress. The scores on the Malaise Inventory indicated that the experimental group throughout, and the control group at Pre 2, to be above the cut off for psychiatric disturbance. In comparison with a study by Sloper et al. (1991) of parents with a child with Down's syndrome (fathers score on MI = 3.76, mothers score on MI = 4.94) and a study by Rutter et al. (1970b) of physically ill mothers with children who had neuro-epileptic disorders, (MI = 4.59), the carers in the current study showed generally higher levels of malaise for those in the experimental group (Pre = 6.23 and Post = 6) and at Pre 2 for those in the control group (5.10), although at the other time points the levels were lower for the Group B participants (Pre 1 = 4.87 and Post = 4.37). Also, for the Caregiver Strain Index, the scores in the current study for the experimental group (pre = 5.58 and post = 4.72) and in the control group (Pre 1 = 4.68 and Pre 2 = 4.29) were above the mean reported by the scale authors (3.52) but dropped down at post intervention for the control group (3.12).

A final consideration as to why so little impact was identified is the variation in how the health checks were administered within the general practices. The practices were asked to administer the health checks in whatever way the practice preferred, as long as a general practitioner took ultimate medical responsibility. It had been assumed initially that, for medical reasons, the only practice member who could conduct the physical examination would be the GP and, therefore, all patients would automatically see the GP for this part of the health check. However, a few practices in the Dyfed Powys Health Authority had nurse practitioners who were fully trained in additional medical procedures and regarded by the GPs in those practices to be able to conduct a physical examination. In these instances, the GPs took a background role and were consulted only if certain health needs were identified.

The high involvement of the nurses was not necessarily a disadvantage for the patients, although, as previously mentioned, it is possible that some carers may have been disappointed by the lack of contact with the doctor. Previous health check studies have suggested that practice nurses have a more positive attitude towards health checks (Chew et al., 1994; Tremellen, 1992) and, as any health problems identified were automatically referred on, the GP still took ultimate responsibility. During the audit process, it was possible to estimate the approximate number of health checks conducted solely by the nurse, doctor or by them working together. For the majority of practices, the doctors conducted the health checks, sometimes with the practice nurse assisting with the initial health promotion information. It was not clear at the audit interview exactly who had done which parts of the health check but, for the majority of practices, the GPs seemed to have, at least, performed the physical examination. Three practices in Dyfed Powys appeared to have given the primary responsibility to the practice nurse or a qualified nurse practitioner. Community nurses conducted the health checks in two of the practices: in the first practice the doctors were only consulted if there was a health need found and in the second practice the doctor did the physical examination.

However, in examining the data from each of the practices as to the number of patients found to have health needs identified, there did not seem to be any obvious effect related to who conducted the health checks. The two practices where the practice nurse took a primary role found no patients with unidentified health needs (but these practices only saw one patient each) and when the nurse practitioner conducted the health checks, just under half the patients required some form of treatment. However, in terms of the number of health needs identified there was some difference. Of the eleven patients who had 3 or more health needs identified, over half of these were from one of the practices where the community learning disability nurse was involved. This learning disability nurse had been previously working with the primary care practice and therefore was keen to be involved with the current project. It also became clear that she had taken a lead in ensuring contact between the patients and the primary care team and had facilitated the health check process, which is a role that has been highlighted in the policy documentation 'Valuing People' (Health, 2001), which suggests that community learning disability nurses are well placed for the position of "health facilitator". Moreover, a recent study looking at the effectiveness of conducting health checks with the combined skills of the GP, a specialist learning disability nurse and a consultant psychiatrist found a high level of unmet need (Cassidy, 2002).

Thus, there may have been considerable variation between the primary care teams in terms of how thoroughly the health checks were conducted, and, so, it cannot be assumed that the process of the health check and, therefore, the intervention was the same in all practices. For the purposes of research, it may have been ideal to control for such variation by, for instance, arranging for the same health professional to conduct all the health checks. However, this would not only be unrealistic in terms of a health professional's time, it would also not be measuring the impact of a health check in real practice.

4.5 Comparison with Other Health Check and Screening Studies

Approximately half of the subjects in the current study had a previously unidentified health need identified during the health check process. Other health check and health screening studies have found a greater percentage of individuals to have unmet needs prior to screening that warranted action by a health professional. Webb & Rogers (1999) conducted health checks with individuals in New Zealand through the existing primary care system and found that 73% had previously unidentified health needs. Cassidy, et al. (2002), using health checks, found that 94% of individuals with a learning disability had a health need that required some form of treatment in a single practice in the UK. Other screening programs organised by community learning disability nurses have identified rates of referral to the primary care team of 91% (Hunt, et al. 2001) and 54% (McConkey et al., 2002): in both of these studies the number of patients who actually received some form of treatment was reported as even higher, as in the first the remaining 9% of patients were treated by the community teams, and in the second additional referrals were also made to other health professionals (e.g. podiatrist, optician, health promotion, audiology, dentist and learning disability specialists).

There are two possible explanations as to why fewer previously unidentified health needs were found during the health check process in the current study. Firstly, the high involvement of the community learning disability teams in the other studies (with the exception of the work of Webb & Rogers (1999)) may have resulted in the health checks being conducted more thoroughly than when conducted predominantly by the primary care team. An alternative explanation is that the practices taking part in the current study may have had a special interest in the health care of this population and, therefore, may have been more skilled at identifying health needs through the existing level of care.

With respect to the involvement of the community learning disability teams, in the study by Hunt et al (2001), the community learning disability nurses ran a nurse led drop in centre and in the work by McConkey et al (2002), the health screening service was run primarily by learning disability nurses. Similarly, in the work by Cassidy et al (2002), the health checks were conducted by a learning disability psychiatrist, a GP and a learning disability nurse working as a team. In the current study a greater number of health needs were found in the practice where the community learning disability nurse was involved, which may suggest that a greater level of specialist knowledge as a possible factor in detecting unmet health needs. However, the study conducted by Webb & Rogers (1999) utilised the existing health care system in New Zealand to perform the health checks and still achieved a detection rate of 73% of unmet health needs. A different style of general practice care exists in New Zealand, where patients are not registered with a primary care practice based on residence, and instead can visit which ever practice they prefer for each consultation. It could be suggested that this system does not place the same level of responsibility on the primary care team and this may result in a lower level of ongoing care in terms of regular consultations. It is possible that these aspects of the health care system in New Zealand may have allowed a greater number of health needs to go unrecognised prior to the health check.

As well as the advantage the community learning disability team has of the target population compared to the primary care team, in terms of specialist knowledge an additional consideration is that general practitioners and other members of the primary care team may be lacking in confidence in the treatment of individuals with a learning disability (Lennox, Diggens et al. 1997; Stanley 1998). McConkey and Truesdale (2000), suggested that this may be due to a generally low level of contact between the primary care and specialist teams in the working environment. A recent study suggested that practice nurses feel that the provision of health care extends beyond the domain of the primary health care team, and that a partnership with the community learning disability teams would best serve the needs of this population (Powrie 2003). McConkey et al. (2002), found that GPs who had received one or more referrals from a screening program team were more positive about the use of health screening than those who had not, and also viewed more favourably the possibility of providing a screening process in the future The authors suggested that this was due to the referral letters reassuring the GPs that the conditions were similar to those found in the general population, which increased their confidence to treat this population. This might suggest that collaboration between the primary care team and the community learning disability team best serves the needs of this population.

A further explanation of why the current study identified a lower level of unmet need than other health check studies may lie with the practices that chose to take part. Three hundred and twenty four practices were contacted initially to take part on the current study, of which 40 chose to take part. This could suggest a greater interest specifically in the health of this population amongst practices that chose to participate. Likewise, practices interested in the process of administering health checks to the learning disability population maybe more aware of the additional health needs of these individuals. However, given this, the current study still identified an unmet need in half of the individuals. If the primary care teams with an awareness and concern for this population still identified such a high level of unmet health needs, this would suggest the need for further studies looking at the primary care teams that are less aware of the needs of learning disabled population, although to identify and recruit such practices may prove difficult.

Although the current study may have found a lower level of unmet need in comparison with other research, the types of health needs identified were similar to those identified in other studies. Firstly, there was a high rate of health promotion actions identified during the health check process, and secondly, the level of health actions related to sensory impairment was particularly high. As part of health promotion, it was found that half of the individuals with Down's Syndrome had not had a thyroid function test prior to the health check and, in many instances, GPs were not aware that this should have taken place on an annual basis. As similar levels of thyroid function testing were found some years ago in the studies of Jones & Kerr (1997) and Piachaud et al., (1998), it would seem that GPs have not become more aware of the need to perform this testing. The lack of knowledge about the need for regular thyroid function testing for individuals with Down's Syndrome should be of concern, especially as the risk for individuals with Down's Syndrome for hypothyroidism is well documented in the literature (Mani 1988; Rooney and Walsh 1997; Van Allen, Fung et al. 1999) and two of the individuals tested in the current study were, indeed found to have hypothyroidism. It could be argued that this may be an example of the difficulties in disseminating the learning disability literature to other health care professionals (Aspray, Francis et al. 1999). However, of the three papers referenced above, the most recent was taken from the International Journal of Medical Science, a mainstream medical publication. It is to be hoped that that, as the learning disabled population is established firmly as the responsibility of general practice, more research relating to their health care will move into the mainstream journals of medicine and not be solely disseminated in psychiatric and other specialist journals.

The current study found that a low level of cervical cytology was conducted, which supports previous research and may suggest a reluctance on the part of health professionals to perform such procedures, possibly due to issues around consent. Previous research investigating the health care of women with a learning disability has highlighted the low levels of cervical cytology conducted within primary care (Band, 1998). In the current study, only 7% females had received a smear test, with a further 26% indicated but not done. The figures by Mencap give a level of cervical screening of 3% for those in family homes and 17% for those in staffed housing (Band 1998), which would indicate that the rate of 7% in the current study is slightly lower than would have been expected with a high proportion of individuals in residential accommodation in the sample. Moreover, two thirds of the females in the current study were found to be clinically not indicated to have a smear conducted, a much higher proportion than found by Shaughnessy (1999) in a study investigating the cooperation of learning disabled women with a smear test, where 56% were willing to cooperate and only 20% were found to be not indicated due to underdevelopment or an intact hymen. The impression gained during the audit interviews in the current study was that many members of the primary care team were concerned not to put an individual through such a distressing procedure if it was not obvious that the person was sexually active. This reluctance on the part of health professionals to conduct cervical screening may have been due to issues around consent, as also discussed in the study conducted by Minihan et al. (1993), which highlighted one of the difficulties for health professionals as distinguishing between fear of a medical procedure and a patient's legal right to refuse treatment. It is possible that the presence of challenging behaviour was a factor, as when the health check forms were re-examined for any relationship between behaviour problems and cervical cytology, half of the females who were indicated for a smear but did not received one, had challenging behaviour, even though individuals with challenging behaviour accounted for only 16% of the total sample. Particularly for individuals with communication difficulties or behaviour problems, health professionals may have tended to be cautious and opted to conduct the smear tests only where there was a clear indication of sexual activity. However, a patient's difficulties with communication and possibly being accompanied by a protective parent or a member of staff who did not know the individual well may not have yielded very accurate information on the individual's sexual activity, and thus could lead to these individuals being overlooked in terms of necessary health promotion. Likewise, the presence of difficult behaviour does not render the individual as sexually inactive and again these individuals may not be receiving a protective level of health promotion.

The only patient recorded as receiving a mammography directly as a result of the health check was subsequently diagnosed with breast cancer. As mammography screening is conducted by breast screening clinics, where patients are invited to attend, the primary care teams do not have direct control over whether or not a mammography is performed. However, the findings of this study do highlight the importance of breast screening and checking. Other studies have found breast abnormalities in 6.5% of the females screened with learning disabilities (Barr, Gilgunn et al. 1999). Although 84% of the female patients on the current study had the full breast examination as part of the health check, 16% did not. There has been some debate amongst the health professionals as to the effectiveness of nurses performing breast checks, as a large number of women identify abnormalities themselves and breast checks may be providing false reassurance (Department of Health 1998). However, an exception was made for particular groups including those with learning disabilities, as it cannot be assumed that individuals with a learning disability are able to take such responsibility for their own health (Royal College of Nursing, 1995). The reliance on carers to notice relevant breast changes warrants additional attention by nurses to check the individual's breasts, educate carers and assist participation in national screening programs (Royal College of Nursing, 1995). Thus breast screening in the learning disabled population may be of greater concern than in the general population, as individuals are unlikely to be able to check for any abnormalities themselves and are reliant on the vigilance of carers and health professionals.

Eight serious health needs were identified during the current study: two cases of hypothyroidism; two cases of diabetes; one case of suspected dementia, one case of asthma; one case of necessary cardiovascular monitoring and one case of lung cancer. Five of these conditions were detected purely as a result of the health promotion conducted as part of the health check, which highlights the importance of such testing. The lack of health promotion within the learning disabled population has been reported by previously by several researchers (Whitfield et al., 1996; Kerr et al., 1996). These results support earlier conclusions that learning disabled individuals may not be currently receiving the level of health promotion they require.

Generally the rates of sensory impairment found on the study were similar to the levels identified in other learning disability populations. The current study found that 59% of patients had impaired vision, which was the same rate identified in a recent study of learning disabled individuals (van Splunder, Stilma et al. 2003). A similar rate of cataract was found of 11% in comparison to other studies of 11% (Aitchison, Easty et al. 1990), and 14% (Sacks, Goren et al. 1991). Other studies have reported a rate of total visual impairment of between

15-20% (Beange & Bauman, 1991; Warburg, 1994; Schrojenstein Lantman-de Valk et al., 1997; Kappell et al., 1998; Cooke, 1989; Howells, 1986). It was not possible to draw comparisons in the current study as the requisite full examination by an optician was not part of the health check. However the audit interview reported that 12% of the current sample had not consulted an optician prior to the health check. One doctor described how the local university offered an eye examination service for learning disabled individuals, and that she had just been made aware of this and intended to recommend use of this in the future. It seems likely that, with the high rate of eye abnormalities reported in the literature and the difficulty in measuring the sight of some individuals, opticians and eye specialists are better placed for proper assessment, although referral and advice may be needed from the primary care team.

Twenty percent of individuals had some form of hearing impairment, which is at the top end of the range of 12.3%-24% identified in other studies (Howells 1986; Cooke 1989). Just under a third of individuals required the removal of earwax (31.1%), which was slightly higher than the level of 28% reported by Crandell & Roeser (1993). Other studies of the use of health checks and screening have identified the rates for individuals requiring the removal of earwax of 40% (McConkey et al. 2002), 46% (Hunt et al. 2001) and 50% (Barr et al. 1999). Research has shown the level of earwax to be noticeably higher than that found in the general population (Crandell and Roeser 1993) and, although not a serious threat to health, should be of concern in a population of individuals with communication difficulties. An awareness on the part of primary care teams and carers that this is a common problem for a large proportion of individuals, may reduce the likelihood of a person being unnecessarily handicapped for a length of time by preventable hearing loss.

4.6 Limitations of the Study

Ten limitations to the study are acknowledged. The first limitation is the large attenuation in the sample. Although data were collected on 190 individuals and comparisons with other total population studies indicated that in terms of ability and level of challenging behaviour the sample was comparable, it must be acknowledged that data were not available on a substantial proportion of those who participated at the outset. The second limitation is that, although the practices were randomly approached, the practices were self selecting and this may have skewed the results. However, this is a problem inherent in any study that uses voluntary participants. A related limitation is that patients and carers themselves were also self selecting and this must also be considered as a limitation of the study. A fourth limitation concerns the sensitivity of the measures that were used. Although all are established within the field of evaluation research, they may not have been sensitive enough detect subtle changes. A further limitation concerns the possible differential reactions of carers to the individual having a health need identified: with some perhaps becoming more anxious and others being reassured. It is possible that these opposing reactions may have had the effect of cancelling out or reducing the measurable effect of the intervention. In a similar vein, the responses of the patients themselves to treatment and the resulting impact on their quality of life may have varied, with some undergoing more invasive procedures than others and these differing reactions may also have resulted in a cancelling out or reduction in the measurable effect of the intervention. A further limitation is that in some cases the reaction to treatment may have been delayed, particularly in instances when treatment occurred over a long period of time and the study period may have been of insufficient length to detect this. An additional limitation that must be acknowledged concerns the difficulty in assessing the thoroughness with which the health checks were administered. Different members of the primary care team conducted the health checks, and it is possible that some individuals had a more thorough health check than others, particularly as those conducting the health checks are likely to have had varying degrees of specialist knowledge. This highlights the potential significant variation in intervention, with this or any similar study, and indeed across studies, in the absence of control over the precision of quality of the intervention conducted. The ninth limitation is due to the type of data generated, as it was not possible to apply multivariate methods and, therefore, it was not possible to investigate the complexity of multiple factors associated with client characteristics that may have influenced the impact of the intervention. In a similar vein, the final limitation is that the size of the sample in relation to the number of serious illnesses detected resulted in the size of the data cells becoming small, which prevented more meaningful analysis of the impact of the intervention.

4.7 Recommendations for Future Research

The recommendations arising from the current study for future work in the area fall into five main areas: recruitment; development of measures; possible at risk groups; alternative methods of data collection and which health professionals are best suited to conduct health checks. These will now be explored in more detail. Firstly, with respect to the recruitment of practices, it is possible that further incentives could be found to encourage wider participation in research of this nature. However, it would probably require an actual policy shift to make health checks a requirement within primary care, if evaluation of the impact of health checks by practices that would not otherwise chose to conduct health checks, is to be achieved. Such a change in policy could facilitate research across a range of primary care practices, although, as with any similar research, participation would inevitably remain voluntary. Recruitment of patients could also be enhanced. Rather than relying on interested practices to invite patients to take part, as in the current study, additional methods could also be explored that may increase access to individuals who may be less well known to the primary care team. The use of social services registers to obtain the names of individuals in contact with learning disability services may be one possibility, or alternatively, invitations to participate in the research being distributed through carer groups, voluntary agencies and self-advocacy organisations.

The development of more sensitive measures specifically to assess the effect of a change in health on quality of life is the second main area of recommendation. Researchers have called for the measurement of quality of life to adequately address the long term effectiveness of health checks (Martin & Roy, 1999), and therefore the development of measures to assess subtle changes is needed. Moreover, measures targeted at specific areas of well-being that are likely to be affected by a change in the individuals health status (for example, aspects of language development, communication, irritability, unusual behaviour patterns and so on) need to be developed for and evaluated within the field of health service research. In addition, other measures should be used to assess the more idiosyncratic effects of a change of health status, possibly through direct questioning or qualitative methods of data collection. Repeated measurement over time is also recommended in order to assess changes that may manifest at a later time than directly after treatment, although care would be needed to avoid attributing artifactual changes to intervention effect.

The third area of recommendation concerns the need to assess the impact of health checks on specific at risk groups. Although the current study collected considerable data on patient characteristics, it did not obtain patients' prior medical history or their context within medical services. Further work in this area is recommended to ascertain the effect of health checks on particular at risk groups such as those with known chronic conditions such as epilepsy, asthma and diabetes, as well as those with multiple physical handicaps. It is possible that many of these individuals are already regularly reviewed by their primary care team as a result of the routine monitoring of these conditions or through specialist clinics. Therefore, this also raises the need for research on the impact of health checks to take account of the frequency in which individuals visit the primary care team on a normal basis, in order to ascertain the relative effectiveness of health checks in identifying previously unknown health needs.

A fourth area of recommendation is to explore alternative ways of obtaining information, as the sheer volume of data collection in the current study may have been one cause for the attenuation in the sample. As previously mentioned, measures targeted specifically on the aspects of quality of life likely to be most affected by changes in health, may reduce the overall volume of data required to detect any possible impact on individuals and carers. Staggering the data collection with, for example, some measures administered after three months, others at six months, and so on, would result in more frequent but much shorter research interviews, and many participants may be more amenable to this. Direct interviews with the patients themselves, where possible, may be another method of reducing the intensity of data collection on some primary carers, while yielding additional data that may capture more directly the individual's experience. The latter approach would necessarily be restricted to those people with sufficient levels of expressive and receptive communication, and would need to include the use of pictures and symbols or other communication aids.

The final area of recommendation for future research is the relative effectiveness of different health professionals in conducting the health checks. Research conducted to date has investigated the effect of health checks being undertaken by nurses, general practitioners, community teams and the primary care team as a whole. Each method of administration is like to have different implications in terms of availability, organisation and cost. Also required is investigation into the thoroughness with which health checks are conducted by these various groups and how the different health professionals communicate to manage the individual's care. The work by McConkey et al. (2002) highlights the possible role of the community teams in providing health checks and then making referrals as appropriate to the individual's GP. Research into the mechanisms of referral and outcomes of referral are needed, to ascertain the full potential impact of the health check on an individual's health care, and to identify the most cost-effective and the most efficient methods of safeguarding the health and well-being of this most vulnerable patient group.

4.8 Conclusion

Although health checks clearly had little measured impact on quality of life, their usefulness in detecting unidentified health needs is clearly important. The number of health needs found as a result of routine health promotion should be of particular concern to primary health care teams, given the vulnerability of the learning disabled population to various conditions and illnesses. There is also some suggestion that the health check process itself may reduce some of the strain on family carers who are concerned about the health of the individual in their care. There is clearly a need for some form of regular assessment of individuals' health to ensure access to screening and health promotion for this population, but routine use of health checks conducted annually across the entire population may be an unnecessary use of resources. It may be preferential to identify specific groups of individuals within the learning disabled population for whom regular health checks may be necessary. For example, the more vulnerable individuals with chronic conditions and multiple disabilities and those with severe communication problems may benefit considerably from a thorough examination on a regular basis. For others, more opportunistic health screening may be sufficient, during routine visits to the surgery, as long as the primary care team members are alert to the special health concerns of this group. Thus, the introduction of a battery of measures into primary care, which includes: monitored health promotion, further education of health professionals, greater collaboration with the community learning disability teams and full health checks for specific groups, may enable health professionals to meet fully the health needs of the learning disabled population.

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Appendix 1.

Adaptive Behavior Scale (Part One)

ABS-RC:2

Adaptive Behavior Scale–Residential and Community

Second Edition

azuo Nihira, Henry Leland, and Nadine Lambert

Examination Booklet

xaminer's Name ______________________________

ater's Name ______________________________

ate of Rating ______________________________

etting/Agency ______________________________

General Instructions

NSTRUCTIONS FOR PART ONE

is Scale consists of a number of statements that describe some of the ways people act in different situations. There are several ways of dministering the Scale; these, and detailed scoring instructions, appear in the accompanying Examiner's Manual.

hen completing the Scale, please observe the following general rules:

1. Items that specify "with help" or "with assistance" for completion of the task refer to direct physical assistance.
2. Give credit for an item even if verbal prompting or reminding is needed to complete the task, unless the item definitely states "without prompting" or "without reminder."

me items may deal with behaviors that are clearly against local regulations (e.g., use of the telephone) or behaviors that are not ssible for a person to perform because the opportunity does not exist (e.g., eating in restaurants is not possible for someone who is edridden). In these instances, you must still complete your rating. Give persons credit for the item if you feel certain that they could nd would perform the behavior without additional training if they were given the opportunity to do so.

ere are two types of items in Part One of the Scale. The first requires that you select only the highest level of behaviors exhibited by the erson being rated. For example:

Eating

EM 2 **Eating in Public**

(Circle highest level)

Orders complete meals in restaurants	3
Orders simple meals like hamburgers or hot dogs	[✓ 2]
Orders single items, e.g., soft drinks, ice cream, donuts, etc. at soda fountain or canteen	1
Does not order in public eating places	0

2

otice that the statements are arranged in order of difficulty. Circle the number of the one statement that best describes the most fficult or highest level task the person can usually manage and then record the number in the adjacent box. In this example, the dividual being observed can order simple meals like hamburgers or hot dogs (2) but cannot order a complete dinner (3). Therefore, e "2" is circled and recorded in the box.

e second type of item asks you to read each statement and circle the number corresponding to a "Yes" or "No" response. There may e instances when a statement appears with the item because certain items do not apply to the individual being rated. In those cases, llow the instructions by placing a check mark in the blank provided and circling the values associated with "Yes" or "No" as instructed.

r example:

EM 4 **Table Manners**

(Circle all answers)

f these items do not apply to the individual, e.g., because he or she is bedfast and/or has liquid food only, place a check in the blank and mark "Yes" for all statements.

	Yes	No
Throws food	0	[✓ 1]
Swallows food without chewing	0	[✓ 1]
Chews food with mouth open	[✓ 0]	1
Drops food on table or floor	0	[✓ 1]
Does not use napkin	0	[✓ 1]
Talks with mouth full	[✓ 0]	1
Takes food off others' plates	0	[✓ 1]
Eats too fast or too slow	0	[✓ 1]
Plays in food with fingers	0	[✓ 1]

7

r other items of the second type, positive ratings (i.e., 1) appear under "Yes," with negative ratings (i.e., 0) appearing under "No." In this ample, the ratee "chews food with mouth open" and "talks with mouth full." Thus, the 0s are circled (indicating a "Yes" response) for ese behaviors and the 1s (indicating a "No" response) are circled for all others. The points are summed and the "7" is recorded in e box.

OMAIN I.

ndependent Functioning

A. Eating

ITEM 1 **Use of Table Utensils**

(Circle highest level)

Uses table knife for cutting or spreading	6
Feeds self neatly with spoon and fork (or appropriate alternate utensil, e.g., chopsticks)	5
Feeds self causing considerable spilling with spoon and fork (or appropriate alternate utensil, e.g., chopsticks)	4
Feeds self with spoon—neatly	3
Feeds self with spoon—considerable spilling	2
Feeds self with fingers	1
Does not feed self or must be fed	0

☐

TEM 2 **Eating in Public**

(Circle highest level)

Orders complete meals in restaurants	3
Orders simple meals like hamburgers or hot dogs	2
Orders single items, e.g., soft drinks, ice cream, donuts, etc. at soda fountain or canteen	1
Does not order in public eating places	0

☐

TEM 3 **Drinking**

(Circle highest level)

Drinks without spilling, holding glass in one hand	3
Drinks from cup or glass unassisted—neatly	2
Drinks from cup or glass unassisted—considerable spilling	1
Does not drink from cup or glass unassisted	0

☐

TEM 4 **Table Manners**

(Circle all answers)

If these items do not apply to the individual, e.g., because he or she is bedfast and/or has liquid food only, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Throws food	0	1
Swallows food without chewing	0	1
Chews food with mouth open	0	1
Drops food on table or floor	0	1
Does not use napkin	0	1
Talks with mouth full	0	1
Takes food off others' plates	0	1
Eats too fast or too slow	0	1
Plays in food with fingers	0	1

☐

Toilet Use

EM 5 **Toilet Training**

(Circle highest level)

Never has toilet accidents	4
Has toilet accidents only at night	3
Occasionally has toilet accidents during the day	2
Frequently has toilet accidents during the day	1
Is not toilet trained at all	0

☐

EM 6 **Self-Care at Toilet**

(Circle all answers)

	Yes	No
Lowers pants at the toilet without help	1	0
Sits on toilet seat without help	1	0
Uses toilet tissue appropriately	1	0
Flushes toilet after use	1	0
Puts on clothes without help	1	0
Washes hands without help	1	0

☐

C. Cleanliness

ITEM 7 **Washing Hands and Face**

(Circle all answers)

	Yes	No
Washes hands and face with soap and water without prompting	1	0
Washes hands with soap	1	0
Washes face with soap	1	0
Washes hands and face with water	1	0
Dries hands and face	1	0

☐

ITEM 8 **Bathing**

(Circle highest level)

Prepares and completes bathing unaided	6
Washes and dries self completely without prompting or helping	5
Washes and dries self reasonably well with prompting	4
Washes and dries self with help	3
Attempts to soap and wash self	2
Cooperates when being washed and dried by others	1
Makes no attempt to wash or dry self	0

☐

ITEM 9 **Personal Hygiene**

(Circle all answers)

If these items do not apply to the individual, e.g., because he or she is completely dependent on others, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Has strong underarm odor	0	1
Does not change underwear regularly by self	0	1
Skin is often dirty if not assisted	0	1
Does not keep nails clean by self	0	1

☐

ITEM 10 **Toothbrushing**

(Circle highest level)

Cleans dentures appropriately	5
Applies toothpaste and brushes teeth with up and down motion	5
Applies toothpaste and brushes teeth with sideways motion	4
Brushes teeth without help, but cannot apply toothpaste	3
Brushes teeth with supervision	2
Cooperates in having teeth brushed	1
Makes no attempt to brush teeth	0
Does not clean dentures	0

☐

D. Appearance

ITEM 11 **Posture**

(Circle all answers)

If these items do not apply to the individual, e.g., because he or she is bedfast or non-ambulatory, place check in the blank and mark "Yes" for all statements. ______

	Yes	No
Mouth hangs open	0	1
Head hangs down	0	1
Stomach sticks out because of posture	0	1
Shoulders slumped forward and back bent	0	1
Walks with toes out or toes in	0	1
Walks with feet far apart	0	1
Shuffles, drags, or stamps feet when walking	0	1
Walks on tiptoe	0	1

☐

EM 12 **Clothing**

(Circle all answers)

f these items do not apply to the individual, e.g., because he or she is completely dependent on others, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Wears clothes that do not fit properly if not assisted	0	1
Wears torn or unpressed clothing if not prompted	0	1
Rewears dirty or soiled clothing if not prompted	0	1
Wears clashing color combinations if not prompted	0	1
Does not know the difference between work shoes and dress shoes	0	1
Does not choose different clothing for formal and informal occasions	0	1
Does not wear special clothing (raincoat, overshoes, etc.) for different weather conditions	0	1

☐

Care of Clothing

EM 13 **Care of Clothing**

(Circle all answers)

	Yes	No
Wipes and cleans shoes when needed	1	0
Puts clothes in drawer, chest, or cupboard	1	0
Hangs up clothes without prompting	1	0
Calls attention to missing buttons and holes and/or repairs clothing	1	0

☐

EM 14 **Laundry**

(Circle highest level)

Uses laundromat or home washer or dryer without assistance	3
Puts clothes in washer and dryer; starts it with assistance	2
Sorts clothing with assistance	1
Does not participate in laundry chores	0

☐

Dressing and Undressing

EM 15 **Dressing**

(Circle highest level)

Completely dresses self	5
Completely dresses self with verbal prompting only	4
Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping, Velcro) them with help	3
Dresses self with help in pulling or putting on most clothes and fastening them	2
Cooperates when being dressed by extending arms or legs	1
Must be dressed completely	0

☐

EM 16 **Undressing at Appropriate Times**

(Circle highest level)

Completely undresses self	5
Completely undresses self with verbal prompting only	4
Undresses self by unfastening (unzipping, unbuttoning, unsnapping, Velcro) clothes with help and pulling or taking them off with verbal prompting	3
Undresses self with help in unfastening and pulling or taking off most clothes	2
Cooperates when being undressed by extending arms or legs	1
Must be completely undressed	0

☐

ITEM 17 **Shoes**

(Circle all answers)

	Yes	No
Puts on shoes correctly without assistance	1	0
Ties shoelaces without assistance	1	0
Unties shoelaces without assistance	1	0
Removes shoes without assistance	1	0
Attaches or detaches Velcro on shoes	1	0

☐

G. Travel

ITEM 18 **Sense of Direction**

(Circle highest level)

Goes a few blocks from facility or school ground or several blocks from home without getting lost	3
Goes around facility ground or few blocks from home without getting lost	2
Goes around ground of facility or home alone	1
Gets lost whenever leaving own living area	0

☐

ITEM 19 **Transportation**

(Circle all answers)

	Yes	No
Rides safely in private cars	1	0
Rides on train, long-distance bus, or plane independently	1	0
Rides in taxi independently	1	0
Rides subway or city bus for unfamiliar journeys independently	1	0
Rides subway or city bus for familiar journeys independently	1	0

☐

ITEM 20 **Mobility**

(Circle all answers)

	Yes	No
Can cross street safely, by self	1	0
Can go to school or work unattended	1	0
Can return home from school or work unattended	1	0
Can go to and return from recreation activities unattended (movies, games, etc.)	1	0
Has driver's license	1	0

☐

ITEM 21 **Safety on Street or School Ground**

(Circle highest level)

Shows awareness of possible dangers (e.g., avoids deep water in pool, uses handrail on stairs, does not accept rides from strangers, uses seat belt in cars, etc.)	3
Obeys traffic signals and "Walk/Don't Walk" signs	2
Looks both ways and waits as necessary before crossing the street	1
Fails to recognize possible danger	0

☐

H. Other Independent Functioning

ITEM 22 **Telephone**

(Circle all answers)

	Yes	No
Uses telephone directory	1	0
Uses pay telephone	1	0
Makes telephone calls from private telephone	1	0
Answers telephone appropriately	1	0
Takes telephone messages	1	0

☐

23 **Miscellaneous Independent Functioning**
(Circle all answers)

	Yes	No	
Has ordinary control of appetite, eats moderately	1	0	
Knows postage rates, buys stamps from post office	1	0	
oks after personal health, e.g., changes wet clothing	1	0	
Deals with simple injuries, e.g., cuts, burns	1	0	
Knows how and where to obtain a doctor's or dentist's help	1	0	
Knows about welfare facilities in the community	1	0	☐
Knows own address	1	0	

24 **Safety at Residential Facility or Home**
(Circle highest level)

Asks whether an unfamiliar object is safe to touch or consume	3	
reful about dangers of electrical outlets and sockets	2	
s careful about danger of hot foods and beverages or hot dishes or pans	1	☐
Is not careful about possible danger	0	

PENDENT FUNCTIONING DOMAIN TOTAL
tems 1–24) ☐

MAIN II.
sical Development

sory Development (Observable ability)

25 **Vision (with glasses, if used)**
(Circle highest level)

Has no difficulty seeing	3	
Has some difficulty seeing	2	
Has great difficulty seeing	1	☐
Has no vision at all	0	

26 **Hearing (with hearing aid, if used)**
(Circle highest level)

Has no difficulty hearing	3	
Has some difficulty hearing	2	
Has great difficulty hearing	1	☐
Has no hearing at all	0	

tor Development

27 **Body Balance**
(Circle highest level)
Note: If toe-walker (see item 11h), score 0.

Able to stand on tiptoes for ten seconds if asked	5	
Able to stand on one foot for two seconds if asked	4	
Stands without support for five minutes or more	3	
Stands with support for five minutes or more	2	
Sits without support for ten minutes or more	1	☐
Can do none of the above	0	

28 **Walking and Running**
(Circle all answers)

	Yes	No	
Walks alone	1	0	
Walks up and down stairs alone	1	0	
Walks down stairs by alternating feet	1	0	
Runs without often falling	1	0	☐
Hops, skips or jumps	1	0	

ITEM 29 **Control of Hands**
(Circle all answers)

	Yes	No	
Catches a ball	1	0	
Throws a ball overhand	1	0	
Lifts cup or glass	1	0	☐
Grasps with thumb and finger	1	0	

ITEM 30 **Limb Function**
(Circle all answers)

	Yes	No	
Has effective use of right arm	1	0	
Has effective use of left arm	1	0	
Has effective use of right leg	1	0	☐
Has effective use of left leg	1	0	

PHYSICAL DEVELOPMENT DOMAIN TOTAL
(add items 25–30) ☐

DOMAIN III.
Economy Activity

A. Money Handling and Budgeting

ITEM 31 **Money Handling**
(Circle highest level)

Takes complete care of own money	4	
Makes change correctly but does not use banking facilities	3	
Adds coins of various denominations, up to one dollar	2	
Uses money but does not make change correctly	1	☐
Does not use money	0	

ITEM 32 **Banking**
(Circle all answers)

	Yes	No	
Uses banking facilities independently	1	0	
Maintains account with assistance	1	0	
Can fill out deposit and withdrawal slips	1	0	☐
Has bank card—can use money machine	1	0	

ITEM 33 **Budgeting**
(Circle all answers)

	Yes	No	
Saves money or tokens for a particular purpose	1	0	
Budgets fares, meals, etc.	1	0	
Spends money with some planning	1	0	☐
Controls own major expenditures	1	0	

B. Shopping Skills

ITEM 34 **Errands**
(Circle highest level)

Goes to several shops and specifies different items	4	
Goes to one shop and specifies one item	3	
Goes on errands for simple purchasing without a note	2	
Goes on errands for simple purchasing with a note	1	☐
Cannot be sent on shopping errands	0	

35

Purchasing
(Circle highest level)

Buys own clothing	5	
Buys own clothing accessories	4	
Makes minor purchases without help (candy, soft drinks, etc.)	3	
Does shopping with slight supervision	2	
Does shopping with close supervision	1	
Does no shopping	0	

36

Shopping Resources
(Circle all answers)

	Yes	No	
Has charge card for specific stores	1	0	
general credit cards or other credit arrangements	1	0	
Carries appropriate identification	1	0	☐
Can endorse check	1	0	

DOMAIN TOTAL
Items 31–36) ☐

OMAIN IV.
guage Development

pression

37

Writing
(Circle highest level)

understandable and complete letters or stories	5	
Writes short notes or memos	4	
Writes or prints whole sentences	3	
Writes or prints at least ten words	2	
Writes or prints name	1	☐
Cannot write or print any words	0	

38

Handwriting
(Circle all answers)
m 37 is marked "0," place a check in the blank and mark "Yes" for all statements. ______

	Yes	No	
Writes backwards	0	1	
Reverses some letters	0	1	
Writing is generally illegible	0	1	☐
Unable to hold pencil or crayon	0	1	

39

Preverbal Expression
(Circle all answers)
on is able to say at least a few words, then place a ck in the blank and mark "Yes" for all statements. ______

	Yes	No	
Nods head or smiles to express happiness	1	0	
Indicates hunger	1	0	
Indicates wants by pointing or vocal noises	1	0	
Imitates sounds of objects or animals (choo-choo, bow-wow, etc.)	1	0	☐
Expresses pleasure or anger by vocal noises	1	0	

40

Articulation
(Circle all answers)
on has no speech at all, then place a check in the blank and mark "Yes" for all statements ______

	Yes	No	
Speech is low, weak, whispered, or difficult to hear	0	1	
Speech is slowed, deliberate, or labored	0	1	
Speech is hurried, accelerated, or pushed	0	1	
Speaks with blocking, halting, or other irregular interruptions	0	1	☐

ITEM 41 **Sentences**
(Circle highest level)

Sometimes uses complex sentences containing "because," "but," etc.	3	
Asks questions using words such as "why," "how," "what," etc.	2	
Speaks in simple sentences	1	☐
Speaks in primitive phrases only or is nonverbal	0	

ITEM 42 **Word Usage**
(Circle highest level)

Talks about action when describing pictures	4	
Names people or objects when describing pictures	3	
Names familiar objects	2	
Asks for things by their appropriate names	1	☐
Is nonverbal or nearly nonverbal	0	

B. Verbal Comprehension

ITEM 43 **Reading Comprehension**
(Circle highest level)

Reads books suitable for children nine years or older	5	
Reads books suitable for children seven or eight years old	4	
Reads simple stories or comics	3	
Reads various signs, e.g., "NO PARKING," "ONE WAY," "MEN," "WOMEN," etc.	2	
Recognizes ten or more words by sight	1	☐
Recognizes fewer than ten words	0	

ITEM 44 **Comprehension of Spoken Instructions**
(Circle highest level)

Understands complex instructions involving a decision, "If ___, do this, but if not, do ___."	4	
Understands instructions involving a series of steps, e.g., "First do ___, then do ___."	3	
Answers simple questions such as "What is your name?" or "What are you doing?"	2	
Responds correctly to simple phrases, e.g., "stop," "sit down," "come here"	1	
Is unable to understand even very simple verbal communications	0	☐

C. Social Language Development

ITEM 45 **Conversation**
(Circle all answers)

	Yes	No	
Uses phrases such as "please" and "thank you"	1	0	
Is sociable and talks during meals	1	0	☐
Talks to others about sports, family, group activities, etc.	1	0	

ITEM 46 **Miscellaneous Language Development**
(Circle all answers)

	Yes	No	
Can be reasoned with	1	0	
Obviously responds when talked to	1	0	
Talks sensibly	1	0	
Reads books, newspapers, or magazines for enjoyment	1	0	
Repeats a story with little or no difficulty	1	0	
Fills in the main items on application form reasonably well	1	0	☐

LANGUAGE DEVELOPMENT DOMAIN TOTAL
(add Items 37–46) ☐

DOMAIN V.
Numbers and Time

EM 47 **Numbers**
(Circle highest level)

Performs division and multiplication	6
Does simple addition and subtraction	5
Counts ten or more objects	4
Mechanically counts to ten	3
Counts two objects by saying "one . . . two"	2
Discriminates between "one" and "many" or "a lot"	1
Has no understanding of numbers	0

☐

EM 48 **Time**
(Circle all answers)

	Yes	No
Tells time by regular clock or watch correctly to the minute	1	0
Reads time on digital clock or digital watch correctly	1	0
Understands time intervals, e.g., between "3:30" and "4:30"	1	0
Understands time equivalents, e.g., "9:15" is the same as "quarter past nine"	1	0
Associates time on clock with various actions and events	1	0

☐

EM 49 **Time Concept**
(Circle all answers)

	Yes	No
Names the days of the week	1	0
Refers correctly to "morning" and "afternoon"	1	0
nderstands difference between day-week, minute-hour, month-year, etc.	1	0

☐

UMBERS AND TIME DOMAIN TOTAL
dd items 47–49) ☐

DOMAIN VI.
Domestic Activity

Cleaning

EM 50 **Room Cleaning**
(Circle highest level)

Cleans living area or school area well without prompting	3
Cleans living area or school area well with prompting	2
Attempts to clean living area or school area but not thoroughly	1
Does not clean living area or school area at all	0

☐

EM 51 **Laundry**
(Circle all answers)

	Yes	No
Washes clothing	1	0
Dries clothing	1	0
Folds clothing	1	0
Irons clothing when appropriate	1	0
Can use washer-dryer correctly	1	0

☐

Kitchen

EM 52 **Table Setting**
(Circle highest level)

laces all eating utensils, as well as napkins, salt, pepper, sugar, etc., in positions learned	3
Places plates, glasses, and utensils in positions learned	2
Places silver, plates, cups, etc., on the table	1
Does not set table at all	0

☐

ITEM 53 **Food Preparation**
(Circle highest level)

Can use microwave correctly to prepare a meal	4
Prepares an adequate complete meal (may use canned or frozen food)	3
Mixes and cooks simple food, e.g., fries eggs, makes pancakes, cooks TV dinners, etc.	2
Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc.	1
Does not prepare food at all	0

☐

ITEM 54 **Table Clearing**
(Circle highest level)

Clears table of breakable dishes and glassware	2
Clears table of unbreakable dishes and silverware	1
Does not clear table at all	0

☐

C. Other Domestic Duties

ITEM 55 **General Domestic Activity**
(Circle all answers)

	Yes	No
Washes dishes well	1	0
Makes bed neatly	1	0
Helps with household chores	1	0
Does household tasks routinely	1	0
Can load and use dishwasher correctly	1	0
Can use small, electric kitchen appliances correctly	1	0

☐

DOMESTIC ACTIVITY DOMAIN TOTAL
(add items 50–55) ☐

DOMAIN VII.
Prevocational/Vocational Activity

ITEM 56 **Job Complexity**
(Circle highest level)

Can perform a job requiring use of tools or machinery, e.g., shop work, sewing, etc.	2
Can perform simple work, e.g., simple gardening, mopping floors, emptying trash, cleaning chalkboard erasers, etc.	1
Can perform no work at all	0

☐

ITEM 57 **Work/School–Job Performance**
(Circle all answers)
If "0" is marked in item 56, place a check in the blank and mark "No" for all statements. _____

	Yes	No
Is a careful worker—avoids accidents to self and others	1	0
Looks after tools, equipment, supplies, etc.	1	0
Works steadily and productively	1	0
Is neat and accurate	1	0

☐

ITEM 58 **Work/School Habits**
(Circle all answers)

	Yes	No
Is late for work/school without good reason	0	1
Is often absent from work/school	0	1
Does not complete jobs without constant supervision/encouragement	0	1
Leaves work station/seat without permission	0	1
Grumbles or gripes about work/school	0	1

☐

PREVOCATIONAL/VOCATIONAL ACTIVITY DOMAIN TOTAL
(add items 56–58) ☐

MAIN VIII.
f-Direction

tiative

59 **Initiative**
(Circle highest level)

Initiates most of own activities, e.g., tasks, games, etc. 3
s if there is something to do or explores surroundings, e.g., home, yard, school, classroom, etc. 2
Will engage in activities only if assigned or directed 1
Will not engage in assigned activities, e.g., putting away toys, etc. 0
☐

60 **Passivity**
(Circle all answers)
If these items do not apply to the individual, g., because he or she is totally dependent on others, then place a check in the blank and mark "Yes" for all statements. ____

	Yes	No
Needs constant encouragement to complete task	0	1
Has to be made to do things	0	1
Has no ambition	0	1
Seems to have no interest in things	0	1
Finishes task last because of wasted time	0	1
Is unnecessarily dependent on others for help	0	1
Movement is slow and sluggish	0	1

☐

rseverance

61 **Attention**
(Circle highest level)

ill pay attention to purposeful activities for more than 5 minutes, e.g., playing games, reading, cleaning up 4
Will pay attention to purposeful activities for up to 15 minutes 3
Will pay attention to purposeful activities for up to 10 minutes 2
Will pay attention to purposeful activities for up to 5 minutes 1
Will not pay attention to purposeful activities for as long as 5 minutes 0
☐

62 **Persistence**
(Circle all answers)
If these items do not apply to the individual, e.g., cause he or she is totally incapable of any organized tivities, then place check in the blank and mark "Yes" for all statements ____

	Yes	No
Cannot organize task	0	1
Becomes easily discouraged	0	1
Fails to carry out tasks	0	1
Jumps from one activity to another	0	1
Needs constant encouragement to complete task	0	1

☐

C. Leisure Time

ITEM 63 **Leisure Time Activity**
(Circle highest level)

Organize leisure time activities on a fairly complex level, e.g., going on a fishing trip, arranging to play billiards, scheduling time to do computer games, etc. 4
Has active interest in hobby, e.g., painting, embroidery, collecting stamps, coins, baseball cards, etc. 3
Participates in organized leisure time activity when arranged for him or her 2
Engages in leisure activity on a simple level, e.g., watching TV, listening to radio, etc. 1
Is unable to arrange leisure time activity, even of the simplest nature 0
☐

SELF-DIRECTION DOMAIN TOTAL
(add items 59–63) ☐

DOMAIN IX.
Responsibility

ITEM 64 **Personal Belongings**
(Circle highest level)

Very dependable—always takes care of personal belongings 3
Usually dependable—usually takes care of personal belongings 2
Unreliable—seldom takes care of personal belongings 1
Not responsible at all—does not take care of personal belongings 0
☐

ITEM 65 **General Responsibility**
(Circle highest level)

Very conscientious and assumes much responsibility—makes a special effort; assigned activities are always performed 3
Usually dependable—makes an effort to carry out responsibilities; one can be reasonably certain that assigned activities will be performed 2
Unreliable—makes little effort to carry out responsibilities; one is uncertain that the assigned activities will be performed 1
Not given responsibilities; is unable to carry out responsibilities at all 0
☐

ITEM 66 **Personal Responsibility**
(Circle all answers)

	Yes	No
Usually maintains self-control	1	0
Understands concept of being on time	1	0
Seeks and accepts help on instructions	1	0
Reports (to teachers, supervisor, etc.) if there is a problem	1	0

☐

RESPONSIBILITY DOMAIN TOTAL
(add items 64–66) ☐

MAIN X.

alization

Cooperation
(Circle highest level)

Offers assistance to others	2
Is willing to help if asked	1
Never helps others	0

☐

Consideration for Others
(Circle all answers)

	Yes	No
Shows interest in the affairs of others	1	0
Takes care of others' belongings	1	0
or manages the affairs of others when needed	1	0
Shows consideration for others' feelings	1	0

☐

Awareness of Others
(Circle all answers)

	Yes	No
Recognizes own family	1	0
Recognizes people other than family	1	0
Has information about others, e.g., job, address, relation to self	1	0
the names of people close to him or her, e.g., classmates, neighbors	1	0
the names of people not regularly encountered	1	0

☐

Interaction with Others
(Circle highest level)

Interacts with others in group games or activities	3
with others for at least a short period of time, e.g. showing or offering toys, clothing, or objects	2
acts with others imitatively with little interaction	1
Does not respond to others in a socially acceptable manner	0

☐

Participation in Group Activities
(Circle highest level)

Initiates group activities (leader and organizer)	3
articipates in group activities spontaneously and eagerly (active participant)	2
cipates in group activities if encouraged to do so (passive participant)	1
participate in or withdraw from group activities	0

☐

ITEM 72

Selfishness
(Circle all answers)
If these items do not apply to the individual, e.g., because he or she has no social life or is profoundly withdrawn, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Refuses to take turns	0	1
Does not share with others	0	1
Gets mad if does not get own way	0	1
Interrupts aide or teacher who is helping another person	0	1

☐

ITEM 73

Social Maturity
(Circle all answers)
If these items do not apply to the individual, e.g., because he or she has no social life or is profoundly withdrawn, place a check in the blank and mark "Yes" for all statements. ______

	Yes	No
Is too familiar with strangers	0	1
Is afraid of strangers	0	1
Does anything to make friends	0	1
Likes to hold hands with everyone	0	1
Is at someone's elbow constantly	0	1

☐

SOCIALIZATION DOMAIN TOTAL
(add items 67–73) ☐

SUPPLEMENTAL

Menstruation
(Circle highest level)
(For males, note "No menstruation")

No menstruation	5
Cares for self completely for menstruation without assistance or reminder	5
Cares for self reasonably well during menstruation	4
Helps in changing pads during menstruation	3
Indicates pad needs changing during menstruation	2
Indicates that menstruation has begun	1
Does none of the above	0

☐

Appendix 2.

Aberrant Behavior Checklist

INSTRUCTIONS

Please rate this resident's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behavior is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging his/her behavior, please keep the following points in mind:

(a) Take relative *frequency* into account for each behavior specified. For example if this resident averages more temper tantrums than all other residents in the unit, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.

(b) Consider this resident's behavior with *all* staff, not just yourself. If he/she has problems with others but not with you, try to take the whole picture into account.

(c) Try to consider whether a given behavior interferes with his/her *development*. For example, chronic body rocking may not disrupt other residents or the management of the residential unit, but it almost certainly hinders individual development. Thus, maladaptive behavior should be taken into account as well as acting out behavior.

(d) Raters are encouraged to rely in part upon the observations of others—in particular those who know the resident especially well and those who can observe him/her in other situations such as during other work shifts, when away at school, and so forth.

Do not deliberate too long on each item—your first reaction is usually the right one		Slight problem	Moderate problem	Serious problem
1. Excessively active in house	0	1	2	3
2. Injures self	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other patients and staff	0	1	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums	0	1	2	3
11. Stereotyped, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable ("grizzly" or "whiny")	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizzare in behavior	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression; lacks emotional reactivity	0	1	2	3

		Not a problem	Slight problem	Moderate problem	Serious problem
21.	Disturbs others	0	1	2	3
22.	Repetitive speech	0	1	2	3
23.	Does nothing but sit and watch others	0	1	2	3
24.	Uncooperative	0	1	2	3
25.	Depressed mood	0	1	2	3
26.	Resists any form of physical contact	0	1	2	3
27.	Moves or rolls head back and forth	0	1	2	3
28.	Does not pay attention to instructions	0	1	2	3
29.	Demands must be met immediately	0	1	2	3
30.	Isolates himself/herself from other residents	0	1	2	3
31.	Disrupts group activities	0	1	2	3
32.	Sits or stands in one position for a long time	0	1	2	3
33.	Talks to self loudly	0	1	2	3
34.	Cries over minor annoyances and hurts	0	1	2	3
35.	Repetitive hand, body, or head movements	0	1	2	3
36.	Mood changes quickly	0	1	2	3
37.	Unresponsive to ward activities (does not react)	0	1	2	3
38.	Does not stay in seat during lesson period	0	1	2	3
39.	Will not sit still for any length of time	0	1	2	3
40.	Is difficult to reach or contact	0	1	2	3
41.	Cries and screams inappropriately	0	1	2	3
42.	Prefers to be alone	0	1	2	3
43.	Does not try to communicate by words or gestures	0	1	2	3
44.	Easily distractible	0	1	2	3
45.	Waves or shakes the extremities repeatedly	0	1	2	3
46.	Repeats a word or phrase over and over	0	1	2	3
47.	Stamps feet while banging objects or slamming doors	0	1	2	3
48.	Constantly runs or jumps around the room	0	1	2	3
49.	Rocks body back and forth	0	1	2	3
50.	Deliberately hurts himself/herself	0	1	2	3
51.	Pays no attention when spoken to	0	1	2	3
52.	Does physical violence to self	0	1	2	3
53.	Inactive, never moves spontaneously	0	1	2	3
54.	Tends to be excessively active	0	1	2	3
55.	Responds negatively to affection	0	1	2	3
56.	Deliberately ignores directions	0	1	2	3
57.	Throws temper tantrums when he/she does not get own way	0	1	2	3
58.	Shows few social reactions to others	0	1	2	3

Individual Items with Specific Examples

Listed below are the individual items making up the ABC. Following each item are specific descriptions of the behavior(s) that help to characterize that item. Users should familiarize themselves with these descriptions before completing the scale.

1. Excessively active on ward
   Active to the point of disruption; pushes chairs runs or walks all over the place. Does not sit still.

2. Injures self
   Any self-inflicted repetitive action that leads to lacerations, bruising, or abrasions of the person's own body. Examples include headbanging, eye-gouging, biting, scratching, self-pinching and punching, rectal digging, and hair-pulling.

3. Listless, sluggish, inactive
   Often needs physical prompting to move or to do things.
   Consistently tired or sleepy.

4. Aggressive to other patients and staff
   Inflicts pain or injury on others through words or actions.
   Examples include pushing, shoving, hitting, throwing objects or screaming at staff or other patients, bullying others (physically or verbally), biting, and scratching.

5. Seeks isolation from others
   Does not engage in interaction with others. Uncommunicative, moody, hides or finds a quiet spot by oneself. Sits in corner or moves away when approached by others.

6. Meaningless, recurring body movements
   Body movements with no apparent desirable or adaptive consequences (e.g., body rocking).

7. Boisterous
   Inappropriately noisy and rough. Examples include shrieking, yelling, and pushing during play.

8. Screams inappropriately
   Screams for no apparent reason. May be attention seeking.
   Usually shows no signs of being upset.
   Does not include screaming when pain is experienced (e.g., injections).

9. Talks excessively
   Talks much of the time. Usually makes sense but this is not a necessary condition. May be repetitive and sound like a "broken record". Often attention seeking.

10. Temper tantrums
    Screaming, crying in anger, striking out, stamping feet.

11. Stereotyped, repetitive movements
    Repetitive movements with no apparent desirable consequences.
    Examples include head rolling, hand waving, complex finger movements, tapping hands on body and bouncing.

12. Preoccupied; stares into space
    Daydreams; requires several prompts to get the person's attention.

13. Impulsive. Acts without thinking
    Acts suddenly or spontaneously without adequate consideration. Rash and "slapdash".

14. Irritable
    Grizzly or whiny; complains in a childish way. Cries with little provocation. Gets upset over minor matters.

15. Restless, unable to sit still.
    Continually standing up, sitting down, moving.

16. Withdrawn
    Prefers solitary activities. Is socially an isolate; quiet to the extreme.

17. Odd, bizarre in behavior
    Engages in ritualistic repetitive behavior.

18. Disobedient; difficult to control
    Non-compliant to staff. Can become stubborn or aggressive if a demand is made of the person.

19. Yells at inappropriate times.
Unpredictable, inappropriate vocalizations. May not necessarily be attention seeking in nature.

20. Fixed facial expression; lacks emotional reactivity.
Does not exhibit changes in emotion even when prompted (i.e., tickled, pushed, hurt). Flat affect.

21. Disturbs others
Disruptive; interferes with on-going activities in residential unit, classroom, or work environment.

22. Repetitive speech
Vocal sterotypy; vocalizes certain words, phrases or sentences repeatedly; *may* be echolalic.

23. Does nothing but sit and watch others
Unresponsive to social play; may be depressed.

24. Uncooperative
Refuses to obey simple orders.

25. Depressed mood
Does not react to affection or other social stimuli. Has a flat affect. Sad. Tearful. Little eye contact.

26. Resists any form of physical contact.
Moves away when approached by others. Obviously distressed when held by staff. Tends to be aloof.

27. Moves or rolls head back and forth.
Repetitive movement with no apparent desirable consequences.

28. Does not pay attention to instructions.
Needs several verbal and physical prompts. Does not include those patients who lack receptive language.

29. Demands must be met immediately.
Is used to having own way; becomes upset or has tantrums when demands are not met immediately.

30 Isolates himself/herself from other patients.
Has difficulty in socializing. May interact with others but only if encouraged.

31. Disrupts group activities.
Engages in disruption and upsetting others in a group, throws equipment about; joins in late and wants group's attention.

32. Sits or stands in one position for a long time.
Purposeless standing or sitting. May be bored, depressed, or totally withdrawn.

33. Talks to self loudly.
Rated when it is obvious that the person is not in conversation with other residents or staff. Must consist of real words although these need not make sense.

34. Cries over minor annoyances and hurts.
Overly sensitive to minor irritations. Crying (or whining), not justified by the discomfort experienced. Some workers may refer to this as being "overly emotional".

35. Repetitive hand, body, or head movements.
Self-stimulatory behavior with no apparent desirable consequences. Stereotyped behavior.

36. Mood changes quickly.
Has sudden mood swings. May laugh, cry, or scream for no obvious reason.

37. Unresponsive to ward activities (does not react).
Does not respond to activities even when encouraged; continues to do nothing or to engage in previous activity or to isolate self from others.

38. Does not stay in seat during lesson period.
Wanders around when (s)he is supposed to be stationary or seated or engaged in some activity.

39. Will not sit still for any length of time.
Overactive, physically restless.

40. Is difficult to reach or contact.
Has autistic tendencies. Lacks eye contact. Unresponsive to social interaction.

41. Cries and screams inappropriately.
Cries or screams when the circumstances do not warrant this. (Does not include crying or screaming when pain is experienced). Highly "emotional".

ers to be alone.
ociable, shy, withdrawn. Actively isolates
f from others.

s not try to communicate by words or
ures.
erved. Subject does not communicate
es, needs, etc., even though able to
municate verbally, by sign language, or by
ure.

y distractable.
s concentration, unmotivated, limited
tion span.

s or shakes the extremities repeatedly.
otyped behavior involving arms, fingers,
and toes. No apparent desirable
equences. May be ritualistic in nature.

s a word or phrase over and over.
a broken record. Says the same thing,
y not appropriate or relevant to what is
on, over and over.

s feet while banging objects or slamming

s making noises or annoying staff; acting
xpresses frustrations. Temper tantrums.

tly runs or jumps around the room.
ively energetic. Physically over-active.

body back and forth.
otyped behavior with no apparent
ble or adaptive consequences.

50. Deliberately hurts himself/herself.
Includes self-injurious behaviors, excessive masturbation, self-mutilation. Need not necessarily result in bleeding, lacerations or cuts.

51. Pays no attention when spoken to.
Non-compliant and unresponsive. Does not include being deaf.

52. Does physical violence to self.
Any physical form of self-injury.

53. Inactive, never moves spontaneously.
Lethargic, depressed, abnormally prone to stay in one place.

54. Tends to be excessively active.
Constantly on the move, overly energetic.

55. Responds negatively to affection.
Does not like to be held, cuddled, kissed, or stroked.

56. Deliberately ignores directions.
Strong willed, disobedient, hears instructions but pretends not to.

57. Throws temper tantrums when he/she does not get own way.
Screams, stamps feet, gets aggressive if subject's requests or wishes are not met.

58. Shows few social reactions to others.
Emotionally unresponsive, asocial, tendency to withdraw from others.

Appendix 3.

Disability Assessment Schedule

Brief Ability/ Disability Assessment Scale

Instructions

Please circle appropriate code throughout. Items specifying 'with help' mean direct physical help, continual prompting or dependence on another person for completion of task. A general prompt to begin a task is NOT counted as 'with help'.

1: MOBILITY

(degree of ambulance is being assessed, therefore help with walking because of blindness or fits should NOT be recorded as incapacity in walking. 'With help' here means help from another person OR appliances (wheelchairs, sticks, but NOT callipers).
CODING NOTE: If a) 3 is recorded, then also record b) 3.

CAN THE CLIENT GET AROUND: -

a) by him/herself:

1. Not at all	2. Not upstairs	3. Upstairs and elsewhere

b) with help:

1. Not at all	2 .Not upstairs	3. Upstairs and elsewhere

2: CONTINENCE

(incontinence due only to epileptic fits should not be recorded)
CODING NOTE: 'Frequently' = twice weekly or more.
'Occasionally' = once weekly or less.

DOES THE CLIENT:-

a) wet himself/herself at night:

1. Frequently	2. Occasionally	3. Never

b) soil himself/herself at night:

1. Frequently	2. Occasionally	3. Never

c) wet himself/herself in the day:

1. Frequently	2. Occasionally	3. Never

d) soil himself/herself in the day:

1. Frequently	2. Occasionally	3. Never

e) TOILETTING: -

1. Need daily toiletting	2. Ask to go to the toilet	3. Go to the toilet alone

3: SELF HELP

CODING NOTE: **FEEDING** - Code '3' if client eats without undue mess, in reasonable time if left alone and if food is NOT specially prepared after it has left the kitchen e.g. cut up, mashed. Even of assistive devices (plate guards, special handles on cutlery, etc.) are used to feed independently this is still coded as '3'.

IS THE CLIENT ABLE TO:

a) feed himself/ herself:

1. Not at all 2. With help 3.Without help

CODING NOTE: **WASHING** - Code "3" if a male can wash, but has to be shaved. Code "2" if staff have to collect up items for client to use, run and test water, etc.

IS THE CLIENT ABLE TO:

b) wash himself/ herself:

1. Not at all 2. With help 3.Without help

CODING NOTE: **DRESSING** - Code '2' for client needing help with shoelaces, fasteners, tucking in clothes, but '3' if staff need only to generally straighten up client's clothing.

IS THE CLIENT ABLE TO:

c) dress himself/ herself:

1. Not at all 2. With help 3.Without help

4: COMMUNICATION

SPEECH - Ability to use language is being assessed here, not measures of speech defect. Thus a person using sentences should be coded '3' even if speech is difficult to understand.

CAN THE CLIENT SPEAK?

1. Never a word. 2. Odd words only 3. Sentences and normal 4. Can talk but doesn't

ECHOLALIA AND REPETITIVE SPEECH

I) **IMMEDIATE ECHOLALIA** (Repeating words just heard)

0. No speech 1. Occurs daily 2. Less than daily 3. Rare/Never

I) **DELAYED ECHOLALIA** ("Pet" words/phrases used over and over again)

0. No speech 1. Occurs daily 2. Less than daily 3. Rare/Never

III) **REPETITIVE SPEECH** (Frequent talk about same things/same questions)

0. No speech 1. Occurs daily 2. Less than daily 3. Rare/Never

5: BEHAVIOUR PROBLEMS

Rate each behaviour, irrespective of whether or not the client is receiving drugs. Consider both frequency and severity. Items l) and m) only apply to fairly able clients - so try to establish whether the client is 'socially aware' before completing these items. If not, omit questions and code for 'does not occur'. For item j) (objectionable habits) code according to overall level if the person has several relevant behaviours.

CODING NOTE: **FREQUENCY**
1 = Marked: behaviour occurred once or more in past month and continues to be a problem.
2 = Lesser: infrequent occurrence - less than once a month.
3 = No: does not occur/difficult to remember when last occurred.

SEVERITY OF MANAGEMENT PROBLEM
1 = Severe: staff/parents have to intervene, or need help; upsets others; a marked effect on social environment, unacceptable in public
2 = Lesser: staff/parents sometimes have to act in some way e.g. clearing up; calming down, etc.
3 = No: not a management problem.

DOES THE CLIENT HAVE ANY OF THE FOLLOWING PROBLEMS?:-

	FREQUENCY	**SEVERITY**
a) Physically aggressive to others - hits out or attacks	--------	--------
b) Destructive - tears paper, clothing, furniture, etc.	--------	--------
c) Overactive - paces, never or rarely sits still	--------	--------
d) Seeks attention - constantly pesters staff or others.	--------	--------
e) Injures self - biting, picking sores, head banging, etc.	--------	--------
f) Wanders or runs away if unsupervised	--------	--------
g) Screams or makes other disturbing noises e.g. grunts, Shouts, uncontrollable laughter, etc.	--------	--------
h) Temper tantrums or verbal abuse.	--------	--------
i) Disturbs others at night	--------	--------
j) Difficult or objectionable personal habits, e.g. spitting, drooling, smearing, hoarding, sexual behaviour.	--------	--------
k) Scatters or throws objects - creates chaos aimlessly.	--------	--------
l) Anti-social, delinquent - steals, lies, bullies, incites others (must be intentional)	--------	--------
m) Sexual delinquency with social awareness - overt, intentional and inappropriate approaches/flirting; self exposure for sexual stimulation, rape, promiscuity.	--------	--------

6: STEREOTYPED BEHAVIOUR

(Stereotyped behaviour may have been mentioned under behaviour problems, e.g. pacing, self injury, hoarding, etc. These should be rated here also).

CODING NOTE: If a) 2,3, or 4 are coded, then b) and/or c) 1 or 2 must be coded.

a) **CHOICE OF ACTIVITIES** - what does he/she do if allowed to choose own activity?

1. **Nothing** - include "watching " TV without real interest.

2. **Sometimes nothing, sometimes stereotyped.**

3. **Always stereotyped.**

4. **Sometimes stereotyped, sometimes constructive recreational activity.**

5. **Sometimes nothing, sometimes constructive.**

6. **Always constructive/ recreational** - include domestic work, looking at books, talking to others, listening to radio, knitting, etc.

b) **SIMPLE STEREOTYPIES** - simple repetitive activities, e.g. rocking, hoarding unrelated objects, tapping, flicking fingers, string twisting, turning objects, gazing at lights, feeling surfaces, etc.

1. **Behaviour is marked, especially when unoccupied, though may be controlled by close supervision or when fully occupied.**

2. **Present, but a minor aspect of behaviour pattern.**

3. **Minimal or none.**

c) **ELABORATE ROUTINES** - skillfull repetitive activities, e.g. arranging objects in lines, hoarding one type of object for no reason, rigidly following certain routines, talking about some subject e.g. train timetables, etc.

1. **Has elaborate routines of the kind found in early childhood autism** e.g. obsessive behaviour such as arranging furniture in a certain way, always carrying certain items about etc. This must be a marked aspect of behaviour pattern, i.e. practically constant whenever client has the opportunity.

2. **Has minor routines/ obsessional behaviour**, e.g. handwashing, excessive tidiness, refusal to be parted with shopping bag, etc. day or night.

3. **Minimal or none.**

7: QUALITY OF SOCIAL INTERACTION

(Choose one of the following ratings which best describes the person. Consider the behaviour shown towards people the client does NOT know well, as this section is concerned with social interaction with acquaintances and people in general.)

CODING NOTE: Code '7' or '8' if the person interacts normally with at least some others even if the range is restricted e.g. a child with other children of own age, even if contacts with adults are unusual; adults with other residents of trainees, but not with staff. Also code '7' or '8' if a more competent adult interacts well with mental age peers and staff, but not those of a lower level of ability.

Questions:
Is he/ she friendly with others? Does he/ she make the first approach?
Does he/ she join in activities actively or passively?
If left alone, does he/she seek company, or does he/ she remain alone, even for a long period of time?
Is he/ she friendly towards adults?
Does he/ she go to people he/ she knows, but ignore strangers?

1. **Does not interact - mainly aloof and indifferent.**

2. **Interacts to obtain needs - otherwise indifferent.**

3. **Responds to and/ or initiates physical contact only.**

4. **Does not initiate social contact but responds passively if others approach** (include people who appear happy to have people around, though make no obvious approaches or responses).

5. **Makes inappropriate social approaches, which are naïve, peculiar or bizarre. Does not modify own behaviour in the light of the needs, interests or responses of others. Interaction is one-sided.**

6. **Makes appropriate social contacts with staff/ older people, but does not interact with peers, classmates, other residents, etc.**

7. **Children - is shy, but interacts appropriately once shyness is overcome** (do not confuse shyness with aloofness).

8. **Adults - interacts appropriately, but is not gregarious i.e. prefers own company.**

9. **Makes appropriate social contacts - looks up and smiles when approached, enjoys contact with own friends and staff, etc., responds to others' interests and needs, contributes to interaction *to the best of his/ her ability*.** (Even in profoundly handicapped people, this interest in social contact can be recognised).

8: SYMBOLIC ACTIVITIES

CODING NOTE:
For children - Does he/ she use toys to represent real objects, or pretend to be someone else; understand stories or show imagination when modelling/ drawing.
For adults - Is he/ she interested in stories, films, TV; sympathetic to other peoples feelings/ problems; like animals and show concern for their feelings.

In b) where it says no problem the person does activities such as embroidery, chess etc. over and over again but the repetitiveness is no problem and will do other activities when appropriate.

a) **IMAGINATIVE** (pretend play or other symbolic activities)

1. Little or none.	2. Limited.	3. Has a range of such interests.

b) **REPETITIVE SYMBOLIC ACTIVITIES** (same games/ pursuits over and over; reluctant to join in other activities).

0. No symbolic activities	1. Marked repetitive symbolic activities	2. Some tendency but has other play/ pursuits	3. No problem.

Appendix 4.

Psychopathology Instrument for Mentally Retarded Adults

Psychopathology Instrument for Mentally Retarded Adults

Informant : ....

Position/Relationship to client : ....

Interviewer : ....

Date : ....

Instructions

Place an " x" in the appropriate column to indicate whether the item is true (YES) or false (NO) for the person you are assessing.

YES NO

1. Person displays verbal and facial affect that is appropriate to the situation (e.g. smiles or laughs at jokes and evidences appropriate concern when someone tells them of misfortune). ___ ___
2. Adjusts easily to new situations. ___ ___
3. Self-consciousness and a tendency toward being easily embarrassed. ___ ___
4. Has the appearance of being cold and unemotional and lacks sense of humour. ___ ___
5. Anxiety, fearful or tense. ___ ___
6. Blunted, flat or inappropriate affect associated with a general lack of appropriate emotion ality in the voice (e.g., remarking that a close friend had recently died with no change in voice inflection or facial expression). ___ ___
7. The person believes that they are more frequently ill than others. ___ ___
8. Speech that is incoherent due to inability to put words together in a coherent sequence. ___ ___
9. Person generally conforms well to rules and social situations. ___ ___
10. Has sexually assaulted or attempted to sexually assault another person. ___ ___

YES NO

11. Auditory hallucinations. ___ ___

12. Indifferent to praise or criticism or to the feelings of others. ___ ___

13. Dependent, helpless, constantly seeking reassurance or is vain and demanding. ___ ___

14. Exercises sexual excitement over inanimate objects (fetish). ___ ___

15. Mood swings and moodiness. ___ ___

16. Person is non compliant and refuses to conform to rules. ___ ___

17. Typically wears clothing of the opposite sex. ___ ___

18. Excessive dependence evident by subordination of one's needs to those of persons on whom s/he depends. ___ ___

19. Cannot cope with stress. ___ ___

20. Complains of frequent and excessive pain (e.g. head, stomach or backaches). ___ ___

21. Decreased energy: mental and/or physical fatigue. ___ ___

22. Physical illness or the pretext of such an illness is frequently used to avoid unpleasant tasks such as work. ___ ___

23. Has "odd speech" (without loss of association or coherence) i.e. digressive, vague, over-elaborate, circumstantial and metaphorical. ___ ___

24. Fear of a debilitating disease such as cancer despite medical reassurance that such a problem is not present. ___ ___

25. Unusual weight loss in last four months. ___ ___

26. Cannot relax. ___ ___

27. Sense of discomfort about one's sexuality (e.g. unhappy to be/ or feels inadequate as man/woman). ___ ___

28. Shows a preoccupation with suspicions that others are trying to take advantage of him/her. ___ __

	YES	NO
29. Preoccupation with seeing the opposite sex in private situations (e.g. 'Peeping Tom', voyeurism).	___	___
30. Statements of appearance of sadness, loneliness, unhappiness, hopelessness and/or pessimism.	___	___
31. Recent (last few months) marked deterioration in work performance, physical appearance and social relations.	___	___
32. Hostile and aggressive towards others.	___	___
33. Preoccupation with a physical defect out of proportion with reality.	___	___
34. Frequently stated desire to be someone of the opposite sex.	___	___
35. Bizarre delusions.	___	___
36. Considered pleasant to be around.	___	___
37. Easily frustrated by failure.	___	___
38. Withdrawal from social contacts.	___	___
39. Very nervous and jittery.	___	___
40. Constant fear and/or worry.	___	___
41. Person is unable to handle routine responsibilities that are reasonable given their cognitive ability.	___	___
42. Self dramatizes and exaggerates expressions of emotions.	___	___
43. Exposes him/herself in public.	___	___
44. Refrains from the discussion of physical ailments except when appropriate.	___	___
45. Vandalizes or steals the property of others.	___	___
46. Discusses present or past physical complaints to gain favour or attention.	___	___
47. Death wishes and/or hypersensitivity that results in the person crying easily.	___	___
48. The person is antisocial or is considered "obnoxious" in their social interactions with others.	___	___
49. Is outgoing and interacts frequently and appropriately with others.	___	___
50. Social withdrawal evidenced by being less outgoing and evidencing less group participation.	___	___

	YES	NO
51. Frequent complaints of dizziness, chest pains or shortness of breath despite evidence of no physical problem.	___	___
52. Does not evidence sexual hang-ups.	___	___
53. Shy, timid and bashful.	___	___
54. Initial insomnia and restless sleep.	___	___
55. Difficulty concentrating because thoughts wander.	___	___
56. Marked peculiar behaviour such as collecting rubbish, talking to self or hoarding physical objects such as clothes.	___	___

PIMRA

Schizophrenia

6 ....

8 ....

11 ....

31 ....

35 ....

38 ....

56 ....

Total ....

Affective disorder

15 ....

21 ....

25 ....

30 ....

47 ....

50 ....

54 ....

Total ....

Psychosexual disorder

10 ....

14 ....

17 ....

27 ....

29 ....

34 ....

43 ....

Total ....

Adjustment disorder

16 ....

19 ....

32 ....

39 ....

41 ....

45 ....

48 ....

Total ....

Anxiety disorder

3 ....

5 ....

26 ....

37 ....

40 ....

53 ....

55 ....

Total ....

Somatoform disorder

7 ....

20 ....

22 ....

24 ....

33 ....

46 ....

51 ....

Total ....

Personality disorder (reversed scored)

4 ....

12 ....

13 ....

18 ....

23 ....

28 ....

42 ....

Total ....

Inappropriate adjust.

1 ....

2 ....

9 ....

36 ....

44 ....

49 ....

52 ....

Total ....

	S	AfD	PsD	AdD	AnD	SD	PeD	IA	Total
Total Score	....	....	....	....	....	....	....		

Appendix 5.

Index of Community Involvement

INDEX OF COMMUNITY INVOLVEMENT

INSTRUCTIONS

1. Ask "In the past month has (persons name) undertaken each of these activities?"

2. For each activity undertaken, ask "how many times?'

(CIRCLE EACH ANSWER)

Activity in the past month	No	Yes				
		x 1	x 2	x 3	x 4	x 5 +
Social						
1. Had guests to stay (no. of nights)	0	1	2	3	4	5
2. Had family or friends in for a meal	0	1	2	3	4	5
3. Been to a social club	0	1	2	3	4	5
4. Been on a overnight stay to family or friends (no of nights)	0	1	2	3	4	5
5. Had trips out with family or friends	0	1	2	3	4	5
Community						
6. Been to a café	0	1	2	3	4	5
7. Been to a pub	0	1	2	3	4	5
8. Been to a hairdresser	0	1	2	3	4	5
9. Been shopping	0	1	2	3	4	5
10. Been to a church	0	1	2	3	4	5
11. Been to a sports event	0	1	2	3	4	5
12. Been to a cinema	0	1	2	3	4	5
13. Been to a concert or play	0	1	2	3	4	5
14. Been on a bus	0	1	2	3	4	5
15. Been to their bank	0	1	2	3	4	5
16. Been on holiday in the past year	0		2	3	4	5

Number of items rated "YES ____________________

TOTAL SCORE (sum of columns) ____________________

Appendix 6.

Index of Participation in Domestic Life

INDEX OF PARTICIPATION IN DOMESTIC LIFE

INSTRUCTIONS

"Does (person's name) do or help to do any of the following jobs?"

(Put a tick in the appropriate box)

Job	Does alone or with other residents. No staff help. (2)	Helps staff with (1)	Does not do (0).
Shopping for food			
Preparing meals			
Setting table			
Serving meals			
Washing up			
Cleaning Kitchen			
Cleaning living and dining rooms			
Cleaning own bedroom			
Cleaning bathroom and toilet			
Shopping for supplies			
Doing own washing			
Doing own ironing			
Looking after the garden			
Total			

Scoring procedure

1. Add all the √ in each column, 2, 1, and 0.
2. Multiply each number of ticks by number in column.
3. Add score for each column and record in total box.
4. Add totals and record in Total Score box opposite.

Total Score ☐

Appendix 7.

Epilepsy Outcome Scale

EPILEPSY OUTCOME SCALE (EOS)

Concerns about seizures

1. Having one fit right after another	0	1	2	3	4
2. Having more fits than usual	0	1	2	3	4
3. Not seeing it happen, not being there	0	1	2	3	4
4. Other people not noticing what's happening	0	1	2	3	4
6. Trying to keep a proper note of seizures	0	1	2	3	4
7. Having lots of fits	0	1	2	3	4
8. Having fits during the night	0	1	2	3	4
9. Being incontinent	0	1	2	3	4
10. Taking a while to recover after a fit	0	1	2	3	4

Concerns about drugs for epilepsy

11. Getting too many drugs	0	1	2	3	4
12. Being sluggish or drowsy	0	1	2	3	4
13. Never being free from drugs	0	1	2	3	4
14. Drugs causing other health problems	0	1	2	3	4
15. Having no clear guidelines about drugs	0	1	2	3	4
16. Having to give drugs rectally	0	1	2	3	4
17. Getting the balance right to control fits	0	1	2	3	4
18. Becoming dependent on drugs	0	1	2	3	4
19. Changing moods due to drugs	0	1	2	3	4
20. Having fits despite drugs	0	1	2	3	4
21. Trying to cut down or stop a drug	0	1	2	3	4
22. Doctors changing drugs around	0	1	2	3	4
23. Not being asked what I think about drugs	0	1	2	3	4

Concerns about injury

24. Someone else getting hurt	0	1	2	3	4
25. Falling over	0	1	2	3	4
26. Sudden death during a seizure	0	1	2	3	4
27. Being unable to breathe	0	1	2	3	4
28. Fits causing damage to the brain	0	1	2	3	4
29. Having a fatal accident	0	1	2	3	4
30. Breaking bones	0	1	2	3	4

Concerns about daily life

31. Leaving him/her alone	0	1	2	3	4
32. Travelling in the car	0	1	2	3	4
33. Bathing and showering alone	0	1	2	3	4
34. Being out of doors	0	1	2	3	4
35. Not being accepted in public	0	1	2	3	4
36. Not getting the chance to work	0	1	2	3	4
37. Carers having interrupted sleep for others	0	1	2	3	4
38. Lacking privacy	0	1	2	3	4
39. Not being able to go to the toilet alone	0	1	2	3	4
40. Losing confidence	0	1	2	3	4

PLEASE ADD ANY COMMENTS WHICH YOU HAVE HERE

NAME:

DATE COMPLETED.

Appendix 8.

Caregiver Strain Index

CAREGIVER INDEX

The list below contains things that other people have found difficult when helping someone who has a learning disability. Please read the list and tick the boxes at the end to tell me if these things apply to you or not. There are some examples to help you when thinking about your answers.

Please tick YES if the statement applies to you or NO if it does not

	YES	NO
Sleep is disturbed (e.g. because the person I help gets in and out of bed at night)		
It is inconvenient (e.g. helping takes up so much time or it takes me a long time to get to the person to help)		
It is a physical strain (e.g. because of lifting in and out of a chair or because of mental effort required)		
It is confining (e.g. helping restricts free time)		
There have been family adjustments (e.g. because helping had adjusted routine or there has been no privacy)		
There have been changes in personal plans (e.g. not being able to do things you had wanted to such as a new job or going on holiday)		
There have been other demands on my time (e.g. from other family members, work colleagues)		
There has been emotional adjustment (e.g. because of an argument)		
Some behaviour is upsetting (e.g. because of incontinence, because of trouble remembering things or because of accusing people of things)		
It is upsetting to find that the person I care for has changed so much from their former self (e.g. they are a different person from the person they used to be)		
There have been work adjustments (e.g. having to take time off)		
It is a financial strain (e.g. short of money)		
Feeling completely overwhelmed (e.g. because of worry about, concerns about how you will manage, having too much to do)		

Appendix 9.

Malaise Inventory

Malaise Inventory

	Main carer		Spouse	
1. Do you often have backache?	Yes	No	Yes	No
2. Do you feel tired most of the time?	Yes	No	Yes	No
3. Do you often feel miserable or depressed?	Yes	No	Yes	No
4. Do you often have bad headaches?	Yes	No	Yes	No
5. Do you often get worried about things?	Yes	No	Yes	No
6. Do you usually have great difficulty in falling asleep or staying asleep?	Yes	No	Yes	No
7. Do you usually wake unnecessarily early in the morning?	Yes	No	Yes	No
8. Do you wear yourself out worrying about your health?	Yes	No	Yes	No
9. Do you often get in to a violent rage?	Yes	No	Yes	No
10. Do people often annoy and irritate you?	Yes	No	Yes	No
11. Have you at times had twitching of the face, head or shoulders?	Yes	No	Yes	No
12. Do you often suddenly become scared for no reason?	Yes	No	Yes	No
13. Are you scared to be alone when there are no friends near you?	Yes	No	Yes	No
14. Are you easily upset or irritated?	Yes	No	Yes	No
15. Are you frightened of going out alone or of meeting people?	Yes	No	Yes	No
16. Are you constantly keyed up and jittery?	Yes	No	Yes	No
17. Do you suffer from indigestion?	Yes	No	Yes	No
18. Do you suffer from an upset stomach?	Yes	No	Yes	No
19. Is your appetite poor?	Yes	No	Yes	No
20. Does every little thing get on your nerves and wear you out?	Yes	No	Yes	No
21. Does your heart often race like mad?	Yes	No	Yes	No
22. Do you often have bad pains in your eyes?	Yes	No	Yes	No
23. Are you troubled with rheumatism or fibrositis?	Yes	No	Yes	No
24. Do you feel close to a nervous breakdown?	Yes	No	Yes	No

Questionnaire completed for (names) ....

Appendix 10.

Maslach Burnout Inventory

1. I feel emotionally drained from my work

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

2. I feel used up at the end of the work day

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

3. I feel fatigued when I get up in the morning

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

4. I can easily understand how my clients feel about things

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

5 I feel I treat some clients as if they were impersonal objects

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

6. Working with people all day is really a strain for me

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

7. I deal very effectively with the problems of my clients

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

8. I feel burned out from my work

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

9. I feel I'm positively influencing other people's lives through my work

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

10. I've become more callous towards people since I took this job

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

11. I worry that this job is hardening me emotionally

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

12. I feel very energetic

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

13. I feel frustrated by my job

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

14. I feel I'm working too hard on my job

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

15. I don't really care what happens to some clients

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

16. Working with people directly puts too much stress on me

HOW OFTEN	0	1	2	3	4	5	6	
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day	
HOW STRONG	0	1	2	3	4	5	6	7
	Never	Very mild, barely noticeable			Moderate			Major, very strong

17. I can easily create a relaxed attitude with my clients

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

18. I feel exhilarated after working closely with my clients

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

19. I have accomplished many worthwhile things in my job

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

20. I feel like I'm at the end of my tether

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

21. In my work I deal with emotional problems very calmly

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

22. I feel clients blame me for some of their problems

HOW OFTEN	0 Never	1 A few times a year or less	2 Once a month or less	3 A few times a month	4 Once a week	5 A few times a week	6 Every day	
HOW STRONG	0 Never	1 Very mild, barely noticeable	2	3	4 Moderate	5	6	7 Major, very strong

Appendix 11.

Choice Questionnaire

CHOICE QUESTIONNAIRE

Client's Name:______________________________ **Service / residence:**______________________

Interviewer/ person completing checklist:____________________ **Date:**__________________________

COMPLETING THIS QUESTIONNAIRE: Please complete this questionnaire about each client as an individual based on **your own** understanding **of the questions** and your knowledge and experience of the client, **not** by interviewing the client. You can consult others (including the client) or written records if there is some **fact** you simply do not know. But give your own **opinion** and do not ask others what they think. Please base your answers on what really happens in practice, not what is supposed to happen or what is stated in policies.

Some items, such as item 2, have more than one question. This is mainly to help clarify the degree of choice when the person is interviewed by asking much the same question in a slightly different way. You may like to consider these multiple questions when choosing your answer for that item.

SCORING: There are three alternatives for each question. Tick the **one** alternative which best represents the person's situation. If two of the alternatives seem equally appropriate, choose the one with the **lower** score. Each question has its own standards in each scoring category. Overall, the three categories differ in the following way:

- **Category 3**: The person makes the decision all or most of the time **without help or guidance** and is free to choose whatever he or she wants.
- **Category 2:** The person usually decides **with help or guidance**. For instance, the person asks or tells staff about the choice first. The person participates actively in the decision (e.g. is asked for his or her ideas or preferences).
- **Category 1:** Others decide most or all of the time and the person has little or no say. Choose this category if person has little or no say regardless of whether it is staff, family or other residents who make the decision or prevent the person from doing what he/she wants. If the person has had no opportunity to make the decision this would generally be scored as category 1. With item 3, for example, someone who never cooks, never has the opportunity to decide what he or she will cook and so is scored as not making that decision (i.e. category 1).

Scoring for some items includes two or more alternative standards linked by the word **OR**. Assign that score if any one (or more) of the standards for that item are met.

EXAMPLE: Item 2 is about deciding which jobs to do around the house. Take the example of Grahame and Peter who share a flat.

- **Category 3** - Grahame and Peter work out between them which jobs need to be done and who will do them. There is no direct involvement by others (family or staff) in this process other than perhaps the occasional comment or reminder in passing.
- **Category 2** - Grahame, Peter and staff (and/or family) work out which jobs to do and who will do them. They may formalise this into a roster or list. That is, Grahame and Peter participate actively in choosing jobs and staff help them plan.
- **Category 1** - Staff (and/or family) usually tell Grahame and Peter which jobs to do, or they work from a roster or list which has been made up by others (e.g. staff) without consulting Grahame or Peter or asking for their ideas and preferences. Some of the scoring categories for items like item 2 begin "I/we (the residents)". This is because shared responsibilities like housework are often subject to joint decisions. For a person living in a group home where the residents plan the housework with no help from staff, you would choose category 3 if the person about whom you were doing this questionnaire was actively involved in the planning decisions, but category 1 if all the decisions were made by other residents with no input from the person.

CHOICE QUESTIONNAIRE

Client's Name:______________________________ **Service/residence:**________________________

Interviewer / person completing checklist:____________________**Date:**____________ **Tape:**__________

INTERVIEWING: Some items, like item 2, have more than one question to help clarify the degree of choice for that item. Ask each question and wait at least 10 seconds for an answer before asking the next question for that item. Probe responses if necessary to aid accurate scoring. Some suggested probes are listed (in parentheses) after some items, like item 1. These suggested probes in parentheses do not have to be asked if the person's answer is quite clear. However, they can be useful in checking that the person has understood the question correctly and answered accordingly. If the person states that he/she decides you can clarify this response by **asking "Does anyone help you decide/choose about ....?"** if necessary. If the person answers that others decide ask **"Does .... ask you about ....?"** or **"Do you have a say about ....?"**. If the answer is that "we" decide you can ask **"Do you have any say about ....?"**

Explain any words which the person seems not to understand. Use familiar local terms when possible for staff, individual plans etc. Some items, like item 10, include explanations in [square brackets] which can be used as needed.

SCORING: There are three alternatives for each question. Tick the one alternative which best represents the person's situation. If two of the alternatives seem equally appropriate, choose the one with the lower score. Each question has its own standards in each scoring category. Overall, the three categories differ in the following way;

- **Category 3**: The person makes the decision all or most of the time **without help or guidance** and is free to choose whatever he or she wants.
- **Category 2**: The person usually decides **with help or guidance**. For instance, the person asks or tells staff about the choice first. The person participates actively in the decision (e.g. is asked for his or her ideas or preferences).
- **Category 1**: Others decide most or all of the time and the person has little or no say. Choose this category if person has little or no say regardless of whether it is staff, family or other residents who make. the decision or prevent the person from doing what he/she wants. If the person has had no opportunity to make the decision this would generally be scored as category 1. With item 3 for example, someone who never cooks, never has the opportunity to decide what he or she will cook and so is scored as not making that decision (i.e. category 1). Likewise, if the person does not know who makes a given decision give a score of 1 on that item. If the person does not genuinely participate in the decision then he/she may simply not know who actually decides.

Scoring for some items includes two or more alternative standards linked by the word **OR**. Assign that score if any one (or more) of the standards for that item are met.

EXAMPLE: Item 2 is about deciding which jobs to do around the house. Take the example of Grahame and Peter who share a flat.

- Category 3 - Grahame and Peter work out between them which jobs need to be done and who will do them. There is no direct involvement by others (family or staff) in this process other than perhaps the occasional comment or reminder in passing.
- Category 2 - Grahame, Peter and staff (and/or family) work out which jobs to do and who will do them. They may formalise this into a roster or list. That is, Grahame and Peter participate actively in choosing jobs and staff help them plan.
- Category 1 - Staff (and/or family) usually tell Grahame and Peter which jobs to do, or they work from a roster or list which has been made up by others (e.g. staff) without consulting Grahame or Peter or asking for their ideas and preferences.

Some of the scoring categories for items like item 2 begin "I / we (the residents)". This is because shared responsibilities like housework are often subject to joint decisions. For a person living in a group home where the residents plan the housework with no help from staff, you would choose category 3 if the person about whom you were doing this questionnaire was actively involved in the planning decisions, but category 1 if all the decisions were made by other residents with no input from the person.

Acquiescence and recency items must be "passed'. They may be asked before or during the first part of the checklist.

RECENCY ITEMS:

a. Do you live by yourself or with other people?	☐ By myself	☐ With others	**Actual situation: Lives alone / with others**
b. Do you live with other people or by yourself?	☐ By myself	☐ With others	(Circle correct alternative)

ACQUIESCENCE ITEMS

Most mornings do **you** pick what clothes to wear?	☐ Yes.	☐ Sometimes.	☐ No.
Most mornings does **someone else tell** you what clothes to wear?	☐ No.	☐ Sometimes.	☐ Yes.

I DOMESTIC ACTIVITIES, STAFF AND THE OTHER PEOPLE YOU LIVE WITH

		SCORING CATEGORIES	
	3	**2**	**1**
1 Who decides what time you go to bed? (Does anyone **tell** you what time to go to bed? Are there any rules about what time you should go to bed?)	☐ I decide for myself.	☐ I usually decide with help. Sometimes others tell me.	☐ I have a set bedtime. **OR** Others mostly tell me when to go to bed.
2 Who decides which jobs **you** do around the house? Do you have set jobs or a jobs roster? Who works out the roster/set jobs?	☐ I/we (the residents) choose the jobs I/we do.	☐ I/we (the residents) usually choose with help from staff. **OR** I/we help staff make up the jobs roster.	☐ Others mostly tell me. **OR** My jobs are set by a jobs roster or list made up by someone else.
3 When you cook dinner, who chooses what you cook? Do you ask the others who live here what they would like to eat?	☐ I choose (I may check with other residents to see what they do/don't like),	☐ I usually choose with help from staff.	☐ I don't cook dinner (or I only help with cooking). **OR** Others mostly choose what I cook. OR There is a planned menu made up by someone else.

SCORING CATEGORIES

		3	2	1
4	**Can you get yourself a drink or something to eat whenever you want? Any time? Do you have to ask someone first?**	**[ ] Yes. I can have a drink or snack whenever I want.**	**[ ] I can usually have a drink or a snack but I have to ask first.**	[ ] No. I am not usually allowed to have snacks and/or drinks. **OR** I can only have them on special occasions.
5	What rules are there about using the telephone? Can you ring up whenever you want to?	[ ] I can ring up without restrictions whenever the phone is not being used.	[ ] I can usually ring up. I may ask staff first. There may be minor restrictions (e.g. can't talk for too long if others want to use the phone).	[ ] I am unable or not allowed to use the phone. **OR** my telephone use is restricted (e.g. only allowed to ring at specified times or to certain places or limited to local calls only).
6	Who picks the staff to work in your house? (Do you interview new staff to decide who will get the job? Are you asked what you think about new staff?)	[ ] I/we (the residents) are responsible for deciding which staff will be employed (e.g. I sit on interview panels).	[ ] I/we (the residents) participate in choosing staff e.g. I am asked for my views about new staff.	[ ] Others choose the staff. I am not consulted and have no real say about who works in my house.
7	Are there any rules in your house? Who makes up the rules for your house? (Do **not** include rules imposed in the lease or by the landlord.)	[ ] There are no rules (except the landlords rules in the lease). **OR** I/we (the residents) decide the rules. I have a fair say.	[ ] I/we (the residents) decide the rules with help from others.	[ ] Others decide the rules. I have no real say.
8	Do you have your own key to the house? Do staff have keys to your house? Did you give them the key? Who says which people can have a key?	[ ] I have a key. Staff do not have keys. **OR** I/we (the residents) decide who can have a key. I have a fair say.	[ ] I have a key, but others mostly decide who else also has a key.	[ ] I do not have a key. I have no real say about who has a key.
9	Who decides if you can have a pet [like a dog, a bird or goldfish] if you want one? Can you have any kind of pet you want? Do you have to ask anyone before you get a pet?	[ ] I can have any pet I like with no restrictions.	[ ] There may be some restrictions (e.g. on the type of pet) because of my lease/landlord. **OR** I have to ask others first.	[ ] I am not allowed to have a pet. **OR** Others decide and I have no real say.
10	What rules are there about you being by yourself in the house [by yourself and **without staff]**? Can you be by yourself in the house if you want to? Anytime? ***If person lives alone score as 3 (i.e. no restrictions).***	[ ] I can be by myself in the house at any time with no restrictions,	[ ] Sometimes I can be by myself (e.g. only in certain situations or for short periods - 1 or 2 hours).	[ ] I am not allowed to be by myself. I am never by myself in the house.

II MONEY AND SPENDING

SCORING CATEGORIES

	3	2	1
11 Who works out your budget so you will have enough money?	[ ] I budget my own money without assistance.	[ ] I have help budgeting my money.	[ ] Others budget my money and I have little say. **OR** I have a fixed budget worked out by others.
12 Who decides **how much** money you take out of your bank account? Can you take out as much as you want? Do you ask anyone how much to take out?	[ ] I decide without help and with no restrictions on how much to withdraw.	[ ] I have help to decide how much to take out **OR** I ask someone how much to take out **OR** I have a limit on how much I can withdraw.	[ ] Others mostly decide how much to withdraw and I am not consulted.
13 When you buy your clothes who chooses which clothes to buy?	[ ] I choose. I buy my clothes with no help.	[ ] I usually choose my clothes with help (e.g. someone usually goes with me).	[ ] Others mostly decide. **OR** Others buy clothes for me.
14 Do you spend some money on gambling like lottery tickets, lotto, poker machines or the TAB? Who decides that you do/don't gamble? (Can you gamble if you want to?)	[ ] I decide.	[ ] I usually decide with help. **OR** Sometimes others may tell me not to.	[ ] I am not allowed to gamble.

III HEALTH

15 Does anyone go with you to see the doctor and the dentist? Who? Does ...... always go?	[ ] I always go by myself or with a friend.	[ ] Staff or family (e.g. parents) come with me to some appointments (e.g. specialists).	[ ] I (almost) always go with staff or family (e.g. parents).
16 Do you drink alcohol like beer or wine? Who decided that you do/don't drink beer/wine? Do you ask anyone if you can drink alcohol? Who? ***(if person drinks:*** Does anyone try to stop you drinking alcohol? ***if person does not drink:*** Why is that?)	[ ] I decided. I am free to drink or not.	[ ] I decided with help **OR** I ask someone (staff or family) first. **OR** I don't drink because of the medication I take or for other medical reasons. **OR** I drink but there are some restrictions on my drinking.	[ ] Others decide (e.g. say I am not allowed to drink).

SCORING CATEGORIES

	3	2	1
17 Do you do exercise or play sport? Who decides that? (Does anyone make you do exercise or sport?)	[ ] I decide.	[ ] I usually decide with help. made to do exercise/sport.	[ ] Others mostly decide. **OR** I am

IV SOCIAL ACTIVITIES, COMMUNITY ACCESS AND PERSONAL RELATIONSHIPS

	3	2	1
18 Does anyone stop you from going out? Is there anywhere you are not allowed to go?	[ ] No-one stops me. I can go wherever I want.	[ ] There are 1 or 2 places I am told not to go to.	[ ] Others often stop me going out. **OR** I am not allowed to go to quite a few places.
19 Who decides what you do in your spare time [when you are not working or at day activities]?	[ ] I decide.	[ ] I usually decide with help.	[ ] Others mostly decide.
20 Who decides if you can go to hotels and clubs? (Does anyone try to stop you?)	[ ] I decide.	[ ] I usually decide with help.	[ ] Others mostly decide. **OR** I am not allowed to.
21 Who decides if you can go and visit your family and friends [whenever it is all right with them]? Do you ask anyone first? Who?	[ ] I can visit whenever it's okay with my family or friends.	[ ] I can visit but I ask someone (other than the person I am visiting) first.	[ ] Others decide. **OR** I am not allowed to visit.
22 Does anyone stop you from looking at sexy [X rated] magazines, videos or movies? (If the person says *"I don't look at those things"*, ask: Who decided that?)	[ ] No. I can look at anything I want (in private). **OR** I decide not to.	[ ] Usually no-one stops me. Occasionally they may ask me not to. **OR** I decided with help not to.	[ ] I am not allowed to. **OR** I am only allowed to look at things some else says are okay.

V WORK / DAY ACTIVITIES

	SCORING CATEGORIES		
	3	2	1
23 Can leave your job/day activity if you want to, do no work and just stay at home? Would you ask anyone first? (Would anyone try to stop you leaving if you wanted to?)	[ ] Yes, I can leave if want to. I don't have to ask anyone else. **OR** I have already left my job/ activity & it was completely my decision.	[ ] I participate in the decision and discuss it with others.	[ ] Others decide. **OR** I am not allowed to leave. **OR** I have never had a job or day activities.
24 Can you be late home from work/day activities? Do you have to tell anyone first or ring up? (Do you get into trouble for being home late?)	[ ] I can come home whenever I like. I don't have to tell anyone first or ring up.	[ ] I can be late if I want, but I am supposed to ask/tell someone first or ring up. I get into trouble if I don't tell someone or ring up.	[ ] Others decide. **OR** I am not allowed to be late. **OR** I have no opportunity to stop off after work & get home late because I never go to work/day activities or because I am driven straight home.
25 What happens if you want to take a day off work/ day activities when you are not sick? You just feel like having a day off. Do you have to ask anyone first?	[ ] It is my decision. (I might lose a days pay).	[ ] I decide with help. I ask others (e.g. staff or family) first.	[ ] Others decide I have no real say. **OR** I am not allowed. I have to go to work/day activities. **OR** I do not make this choice because I never work or attend day activities.

VI OVERALL CHOICE

26 Overall would you say that your life is free so you can choose what you want? All the time?	[ ] Yes definitely.	[ ] Yes, most of the time. Sometimes it is planned for me.	[ ] No. I often cannot do what I want.

Appendix 12.

Diary of Scheduled Activity

	Monday			Tuesday			Wednesday			Thursday			Friday			Saturday			Sunday		
		A	B		A	B		A	B		A	B		A	B		A	B		A	B
9:00 – 9:30																					
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11:30 – 12:00																					

Appendix 13.

SF-36 (proxy version)

SF-36 HEALTH SURVEY

CAREGIVER/PROXY RESPONDENT FORM

INSTRUCTIONS: This survey asks you questions about the patient's health. This information will help keep track of how the patient feels and how well the patient is able to do his/her usual activities. Please answer every question the way you believe best describes the patient's health and feelings.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say the patient's health is:

	(circle one)
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate his/her health in general now?

	(circle one)
Much better now than one year ago	1
Somewhat better than one year ago	2
About the same now as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

(SF-36 Standard U.S. Proxy Version 1.0)

3. The following items are about activities the patient might do during a typical day. Does his/her health now limit him/her in these activities? If so, how much?

(circle one number on each line)

	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking **more than one mile**	1	2	3
h. Walking **several blocks**	1	2	3
i. Walking **one block**	1	2	3
j. Bathing or dressing himself/herself	1	2	3

4. During the past 4 weeks, has the patient had any of the following problems with his/her work or other regular daily activities as a result of his/her physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** he/she spent on work or other activities	1	2
b. **Accomplished less** than he/she would like	1	2
c. Was limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, has the patient had any of the following problems with his/her work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** he/she spent on work or other activities	1	2
b. **Accomplished less** than he/she would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. During the past 4 weeks, to what extent has the patient's physical health or emotional problems interfered with his/her normal social activities with family, friends, neighbors, or groups?

(circle one)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain has the patient had during the past 4 weeks?

(circle one)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

8. During the past 4 weeks, how much did pain interfere with the patient's normal work (including both work outside the home and housework)?

(circle one)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how the patient feels and how things have been with him/her during the past 4 weeks. For each question, please give the one answer that comes closest to the way he/she has been feeling. How much of the time during the past 4 weeks -

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did he/she feel full of pep?	1	2	3	4	5	6
b. Has he/she been a very nervous person?	1	2	3	4	5	6
c. Has he/she felt so down in the dumps that nothing could cheer him/her up?	1	2	3	4	5	6
d. Has he/she felt calm and peaceful?	1	2	3	4	5	6
e. Did he/she have a lot of energy?	1	2	3	4	5	6
f. Has he/she felt downhearted and blue?	1	2	3	4	5	6
g. Did he/she feel worn out?	1	2	3	4	5	6
h. Has he/she been a happy person?	1	2	3	4	5	6
i. Did he/she feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has the patient's physical health or emotional problems interfered with his/her social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

11. How TRUE or FALSE is each of the following statements for the patient?

(circle one number on each line)

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. He/she seems to get sick a little easier than other people	1	2	3	4	5
b. He/she is as healthy as anybody I know	1	2	3	4	5
c. He/she expects his/her health to get worse	1	2	3	4	5
d. His/her health is excellent	1	2	3	4	5

Appendix 14.

SF-36 (standard version)

THE MOS 36-ITEM SHORT-FORM HEALTH SURVEY (SF-36)

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

	(circle one)
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. Compared to one year ago, how would you rate your health in general now?

	(circle one)
Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

U.K. STANDARD SF-36, BOOKLET FORM – PAGE TWO OF FIVE

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking **more than a mile**	1	2	3
h. Walking **half a mile**	1	2	3
i. Walking **one hundred yards**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

U.K. Version of Standard SF-36 Health Survey 5/93

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

U.K. Version of Standard SF-36 Health Survey 5/93

U.K. STANDARD SF-36, BOOKLET FORM – PAGE FOUR OF FIVE

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all	1
A little bit	2
Moderately	3
Quite a bit	4
Extremely	5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

U.K. Version of Standard SF-36 Health Survey 5/93

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

(circle one)

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5

11. How TRUE or FALSE is each of the following statements for you?

(circle one number on each line)

	Definitely True	**Mostly True**	**Don't Know**	**Mostly False**	**Definitely False**
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

U.K. Version of Standard SF-36 Health Survey 5/93

Appendix 15.

Working Methods Scale (revised version)

Working Methods Scale (Revised)

Welsh Centre for Learning Disabilities Applied Research Unit

Part one: Individual planning

a) Is there a meeting at least annually to review the needs of each individual, set goals and initiate plan the required support?

[If Care Assessment or care management is the only form of planning around individuals, please note this and go on to Part Two.]

b) How many residents have had a meeting in:

the last six months? .....
the last 12 months? .....

c) Do the following usually attend the meetings:

individual	
individual's family	
advocate	
keyworker	
residential staff	
day care staff	
community team	
other	

d) Are decisions written down? Yes/No

e) Are decisions circulated? Yes/No

f) How are decisions communicated to staff?

g) Describe how action and progress is reviewed between planning meetings?

h) How are residents involved in the individual planning process?

residents are not usually, or rarely involved	
some residents are involved some of the time/ through parts of the process	
some residents are involved throughout the whole process	
all residents are involved throughout the whole process	

i) How do you involve people with communication difficulties?

Part two: Assessment and teaching

a) Is there a formal system for identifying what residents can and cannot do?

[ask what type of assessment and how often it is done]

b) Are staff involved in teaching?

[ask for brief example]

c) How do you decide what to teach?

[on what information is this based?]

d) Do you have written teaching plans?

[If yes give example. If no go to h]

e) Does the teaching programme include a standard to be achieved?

[e.g. Mark will correctly pick out a £1 coin from several coins, *on at least 3 out of 5 attempts*]

f) Does the teaching programme include a section for recording progress?

g) How often are teaching programmes reviewed?

h) Are residents involved in selecting the skills they wish to acquire?

residents are not usually, or rarely involved	
some residents are involved some of the time/ through parts of the process	
some residents are involved throughout the whole process	
all residents are involved throughout the whole process	

i) How do you involve people with communication difficulties?

Part three: Planning daily/weekly activities

a) How is it decided what residents do on a day to day basis?

[including evenings and weekends]

b) What types of activities are planned for?

[e.g. household, social, leisure' day occupation]

c) Are individuals' likes and dislikes taken into account?

[is this done formally, e.g. at meetings convened for this purpose or through likes/dislikes assessments? Or is it informal?]

d) Do individuals have a written timetable of activities?

[if yes, ask for a copy of one; if no, go to f]

e) How are activity timetables communicated to staff?

f) Is there a way of monitoring/keeping track of the activities each person has been involved in?

[describe]

g) How often are individuals' activities reviewed?

h) How are residents involved in choosing their activities?

residents are not usually, or rarely involved	
some residents are involved some of the time/ through parts of the process	
some residents are involved throughout the whole process	
all residents are involved throughout the whole process	

i) How do you involve people with communication difficulties?

Part four: Staff support of resident activity

a) Is there a standard rota for staff, or is the number of staff on duty decided on the basis of residents' activity timetables?

b) Please describe how staff decide which residents to work with and what needs to be done when they are on duty.

c) Do staff have specific training in how to support resident activity?

[e.g. task analysis, different levels of support]

d) Ask for a copy of a support worker's job description.

Part five: Staff training and supervision

a) Which of the following types of training do staff receive?

induction	
on request/ ad hoc in-service	
regular in-service	
regular refresher	

b) Do staff receive specific training in the following:

individual planning	
resident assessment	
resident activity planning	
involving residents in decisions	
involving residents with communication difficulties in decisions	

c) Please describe how staff training needs are assessed and reviewed.

d) How are individual staff supervised?

[and how often]

e) How are individual staff monitored?

f) How often are individual staff formally appraised?

Appendix 16.

Cardiff Health Check for People with a Learning Disability

Cardiff Health Check for People with a Learning Disability

Date Name

Marital status Ethnic origin

Principal carer Age Sex

Address

Weight (kg/stone)............................ Height (meters /feet) ....

Blood Pressure .... Urine Analysis ....

Smoke (per day) .... Alcohol (units per week) ....

Body Mass Index
(weight in kg / height in m2) .... Cholesterol/
Serum lipids ....

Immunization - People with learning disability should have the same regimes as others and the same contra indications apply. (please circle)

Tetanus in last ten years?	Yes ☐	No ☐
If no has tetanus been given?	Yes ☐	No ☐
Has influenza vaccine been given?	Yes ☐	No ☐
Is Hepatitis B status known?	Yes ☐	No ☐

Result? ....

Cervical screen – people with a learning disability have same indications for cervical cytology as others.

Is a smear indicated?	Yes ☐	No ☐

If yes when was last smear? ...../....../...... When is next due? ....../....../......

What was the result? ....

Mammography – this should be arranged as per local practice.

Has mammogram been performed	Yes ☐	No ☐

CHRONIC ILLNESS - Does your patient suffer from any chronic illnesses.

Diabetes	Yes ☐	No ☐
Asthma	Yes ☐	No ☐

SYSTEMS ENQUIRY – the answer to these will not always be available.

Respiratory cough	Yes ☐	No ☐
Haemoptysis	Yes ☐	No ☐
Sputum	Yes ☐	No ☐
Wheeze	Yes ☐	No ☐
Dyspnoea	Yes ☐	No ☐

Cardiovascular system

Chest pain	Yes ☐	No ☐
Swelling of ankles	Yes ☐	No ☐
Palpitations	Yes ☐	No ☐
Postural nocturnal dyspnoea	Yes ☐	No ☐
Cyanosis	Yes ☐	No ☐

Abdominal

Constipation	Yes ☐	No ☐
Weight loss	Yes ☐	No ☐
Diarrhoea	Yes ☐	No ☐
Dyspepsia	Yes ☐	No ☐
Melaena	Yes ☐	No ☐
Rectal bleeding	Yes ☐	No ☐
Faecal incontinence	Yes ☐	No ☐

Feeding problems Yes ☐ No ☐

C.N.S. – for epilepsy see overleaf

Faints Yes ☐ No ☐

Parasthesia Yes ☐ No ☐

Weakness Yes ☐ No ☐ where ....

Genito- urinary

Dysuria Yes ☐ No ☐

Frequency Yes ☐ No ☐

Haematuria Yes ☐ No ☐

Urinary Incontinence Yes ☐ No ☐

If Yes has M.S.U. been done Yes ☐ No ☐

Would you consider other investigations? Yes ☐ No ☐

Gynae

Dysmenorrhoea Yes ☐ No ☐

Inter menstrual bleeding Yes ☐ No ☐

PV discharge Yes ☐ No ☐

Is patient post menopausal? Yes ☐ No ☐

Contraceptives Yes ☐ No ☐

Other...

EPILEPSY Yes ☐ No ☐

Type of fit ....

Frequency of seizures (fits/month) ..../..................

Over the last year have the fits Worsened ☐ Remained the same ☐ Improved ☐

Antiepileptic medication

Name	Dose/frequency	Levels (if indicated)

Side effects observed in the patient..

....

BEHAVIOURAL DISTURBANCE.

Behavioural disturbance in people with a learning disability is often an indicator of other morbidity. For this reason it is important to record it as it can point to other morbidity.

Aggression yes ☐ no ☐

more than once a month ☐ less than once a month ☐ very infrequently ☐

Self injury yes ☐ no ☐

more than once a month ☐ less than once a month ☐ very infrequently ☐

Overactivity yes ☐ no ☐

more than once a month ☐ less than once a month ☐ very infrequently ☐

Other ....

more than once a month ☐ less than once a month ☐ very infrequently ☐

PHYSICAL EXAMINATION

General appearance

Anaemia Yes ☐ No ☐

Lymph nodes Yes ☐ No ☐

Clubbing Yes ☐ No ☐

Jaundice Yes ☐ No ☐

Hydration Yes ☐ No ☐

CARDIO VASCULAR SYSTEM

Pulse ....beats/min Blood pressure /

Heart sounds .... S.O.A. Yes ☐ No ☐
(describe)

RESPIRATORY SYSTEM

Respiratory rate ....breaths/min

Breath sounds Yes ☐ No ☐

Wheeze Yes ☐ No ☐

Tachypnoea Yes ☐ No ☐

Additional sounds Yes ☐ No ☐

(describe)..

ABDOMEN

Masses Yes ☐ No ☐

Liver Yes ☐ No ☐

Spleen Yes ☐ No ☐

PR indicated Yes ☐ No ☐

Results ....

CENTRAL NERVOUS SYSTEM – It is often difficult and not relevant to perform a full neurological examination, however, people with a learning disability are particularly prone to abnormalities in vision, hearing and communication – a change in function would suggest further investigation is necessary

VISION

Normal vision ☐ Minor visual problem ☐ Major visual problems ☐

Is the carer/key worker concerned?	Yes ☐	No ☐

When did the patient last see an optician? ....../......../........

Is there a cataract?	Yes ☐	No ☐

Result of Snellen chart ....

Any other data ....

HEARING

Normal hearing ☐ Minor hearing problem ☐ Major hearing problem ☐

Is the carer/ key worker concerned?	Yes ☐	No ☐
Does he/she wear a hearing aid?	Yes ☐	No ☐
Any wax?	Yes ☐	No ☐
Does your patient see an audiologist?	Yes ☐	No ☐

Other investigation ....

COMMUNICATION

Does your patient communicate normally?	Yes ☐	No ☐
Does your patient communicate with aids?	Yes ☐	No ☐
Does your patient have a severe communication problem?	Yes ☐	No ☐
Does your patient see a speech therapist?	Yes ☐	No ☐

MOBILITY

Is your patient fully mobile? Yes ☐ No ☐

Is your patient fully mobile with aids? Yes ☐ No ☐

Is your patient immobile? Yes ☐ No ☐

Has immobility been assessed? Yes ☐ No ☐

DERMATOLOGY

Any abnormality? Yes ☐ No ☐

Diagnosis ....

BREAST

Any lumps? Yes ☐ No ☐

Any discharge? Yes ☐ No ☐

Nipple retraction? Yes ☐ No ☐

OTHER INVESTIGATIONS

Are there any further investigations necessary? Yes ☐ No ☐

If yes please indicate ....

SYNDROME SPECIFIC CHECK - Certain syndromes causing learning disabilities are associated with increased morbidity (information can be found in the education pack provided) for this reason it is important to record:

Is the cause of learning disability known? Yes ☐ No ☐

If yes, what is it? ....

Has the patient had a chromosomal analysis? Yes ☐ No ☐

Result? ....

Is the degree of learning disability?

mild ☐ moderate ☐ severe ☐ profound ☐

Is a formalised IQ test available? Yes ☐ No ☐

If yes, what were the results? ……………………………………………………………

If your patient has Down's syndrome he/she should have a yearly test for hypothyroidism.
Has this been done?
Yes ☐ No ☐

OTHER MEDICATION

Drug	Dose	Side Effects	Levels (if indicated)

THANK YOU

Appendix 17.

Cardiff Health Check Audit

Cardiff Health Check Audit

ID

Date

Name

Marital status

Ethnic origin

Principal carer

Age

Relationship to patient

Address

Sex

Name of person accompanying

Length of acquaintance

Relationship to patient

	Undertaken / not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
Weight								
Height								
Blood Pressure								
Urine								
Smoke								
Alcohol								
Cholesterol								
Immunization								
Cervical Screen								
Mammography								

Not undertaken

1. Refused by individual
2. Individual Uncooperative
3. Clinical decision
4. Refused by Carer
5. Other

Undertaken by

1. Doctor
2. Practice nurse
3. Nurse practitioner
4. Learning disability nurse
5. Other

Action planned

1. Continue previous treatment
2. Change previous treatment
3. Introduce treatment
4. Further investigated/ monitor within surgery
5. Referral to specialist
6. Liaise with other professional
7. No further action
8. Patient/ Carer refused intervention.
9. Other

Action taken

1. Planned action taken and successful
2. Planned action taken and unsuccessful
3. Planned action in progress
4. Not undertaken due to patient constraints
5. Not undertaken due to practice constraints
6. Not undertaken due to external agencies constraints
7. Change in planned action

Chronic illness and Systems enquiry

	Undertaken / not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
Endocrine (Diabetes, Thyroid)								
Respiratory system (Asthma)								
Cardiovascul system								
Abdominal system								
Central nervous system								
Genito Urinary								
Gynae								
Vision								
Hearing								
Dental								
Communication								
Mobility								

Not undertaken

1. Refused by individual
2. Individual Uncooperative
3. Clinical decision
4. Refused by Carer
5. Other

Undertaken by

1. Doctor
2. Practice nurse
3. Nurse practitioner
4. Learning disability nurse
5. Other

Action planned

1. Continue previous treatment
2. Change previous treatment
3. Introduce treatment
4. Further investigated/ monitor within surgery
5. Referral to specialist
6. Liaise with other professional
7. No further action
8. Patient/ Carer refused intervention.
9. Other

Action taken

1. Planned action taken and successful
2. Planned action taken and unsuccessful
3. Planned action in progress
4. Not undertaken due to patient constraints
5. Not undertaken due to practice constraints
6. Not undertaken due to external agencies constraints
7. Change in planned action

Physical Examination

	Undertaken / not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
General Appearance								
Respiratory system (Asthma)								
Cardiovascular system								
Abdominal system								
Central nervous system								
Dermatology								
Breast Examination								
Other Investigation								

Not undertaken

1. Refused by individual
2. Individual Uncooperative
3. Clinical decision
4. Refused by Carer
5. Other

Undertaken by

1. Doctor
2. Practice nurse
3. Nurse practitioner
4. Learning disability nurse
5. Other

Action planned

1. Continue previous treatment
2. Change previous treatment
3. Introduce treatment
4. Further investigated/ monitor within surgery
5. Referral to specialist
6. Liaise with other professional
7. No further action
8. Patient/ Carer refused intervention.
9. Other

Action taken

1. Planned action taken and successful
2. Planned action taken and unsuccessful
3. Planned action in progress
4. Not undertaken due to patient constraints
5. Not undertaken due to practice constraints
6. Not undertaken due to external agencies constraints
7. Change in planned action

Epilepsy

	Undertaken / not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
Blood levels								
Medication Review								
Seizure type								
Seizure frequncy								
Any change in Seizure type or frequency								
Were side effects considered								

Is Epilepsy managed by the GP or a specialist? GP SPECIALIST

Behaviour

	Undertaken / not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
Aggression								
Self Injury								
Over activity								
Other								

Not undertaken

1. Refused by individual
2. Individual Uncooperative
3. Clinical decision
4. Refused by Carer
5. Other

Undertaken by

1. Doctor
2. Practice nurse
3. Nurse practitioner
4. Learning disability nurse
5. Other

Action planned

1. Continue previous treatment
2. Change previous treatment
3. Introduce treatment
4. Further investigated/ monitor within surgery
5. Referral to specialist
6. Liaise with other professional
7. No further action
8. Patient/ Carer refused intervention.
9. Other

Action taken

1. Planned action taken and successful
2. Planned action taken and unsuccessful
3. Planned action in progress
4. Not undertaken due to patient constraints
5. Not undertaken due to practice constraints
6. Not undertaken due to external agencies constraints
7. Change in planned action

Syndrome Specific Check

	Undertaken/ not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
Chromosomal Analysis								
Thyroid levels (if appropriate)								
Was the syndrome checklist used from Edu Pack								
Other investigation ………………								

Other Medication

……………	Undertaken / not undertaken	Reason not undertaken	Undertaken by	Previous problem in this area	New problem	Action planned	Action taken	Comments
Medication review								
Did they look for side effects?								

Not undertaken

1. Refused by individual
2. Individual Uncooperative
3. Clinical decision
4. Refused by Carer
5. Other

Undertaken by

1. Doctor
2. Practice nurse
3. Nurse practitioner
4. Learning disability nurse
5. Other

Action planned

1. Continue previous treatment
2. Change previous treatment
3. Introduce treatment
4. Further investigated/ monitor within surgery
5. Referral to specialist
6. Liaise with other professional
7. No further action
8. Patient/ Carer refused intervention.
9. Other

Action taken

1. Planned action taken and successful
2. Planned action taken and unsuccessful
3. Planned action in progress
4. Not undertaken due to patient constraints
5. Not undertaken due to practice constraints
6. Not undertaken due to external agencies constraints
7. Change in planned action

Appendix 18.

Scores for subjects with the triad of social impairment and their carers

Scores for subjects with the triad of social impairment

Presence of the triad of social impairment (Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS Triad Mean Median (Range)	N=40 118.73 118 (40-208)	N=40 117.35 115.5 (17-216)	N=30 129.83 129 (50-205)	N=30 137.40 133 (59.202) *	N=30 140.77 138 (58-227) *1
PIMRA Triad Mean Median (Range)	N=40 13.15 13.5 (4-23)	N=40 12.4 12 (4-27)	N=30 15.47 16 (6-30)	N=30 13.13 12.5 (0-32) *	N=30 12.83 13.5 (1-25) *1
ABC Tot Triad Mean Median (Range)	N=39 35.74 31 (2-87)	N=39 32.85 31 (2-104)	N=31 38.55 32 (5-115)	N=31 36.97 38 (1-83)	N=31 29.71 25 (0-94) *2
ABC TN Triad Mean Median (Range)	N=39 21.56 24 (2-46)	N=39 20.62 19 (2-49)	N=31 24.06 24 (5-51)	N=31 24.97 24 (1-49)	N=31 20.74 19 (0-46) *2
ABC T3s Triad Mean Median (Range)	N=39 3.97 2 (0-18)	N=39 2.90 0 (0-20)	N=31 3.87 0 (0-24)	N=31 2.29 0 (0-11)	N=31 2.06 0 (0-15)
IPDL Triad Mean Median (Range)	N=40 6.25 5.5 (0-21)	N=40 5.88 4.5 (0-20)	N=31 7.68 7 (0-18)	N=31 7.84 9 (0-21)	N=31 8.68 8 (0-18) +
Choice Triad Mean Median (Range)	N=27 47.74 49 (37-71)	N=27 45.19 45 (35-56) *	N=19 49.89 50 (38-59)	N=19 53.53 53 (40-63) * ++Pre ✝✝Post	N=19 45.63 45 (35-61) *1 •2
ICI Triad Mean Median (Range)	N=40 5.62 6 (0-10)	N=40 5.4 5 (0-11)	N=31 7.10 7 (3-11) +	N=31 7.42 7 (4-12) •Pre ••Post	N=31 6.58 6 (4-10) **2 +
ICI freq Triad Mean Median (Range)	N=40 17.35 17.5 (0-36)	N=40 15.23 14 (0-35)	N=31 21.68 22 (5-35) +	N=31 22.77 22 (8-38) •Pre ••Post	N=31 20.52 21 (8-35) *2 ++
Diary A Triad Mean Median (Range)	N=41 2.57 1 (0-13)	N=41 0.79 0 (0-4.5) ••	N=30 2.12 1 (0-18)	N=30 1.3 0 (0-6.5)	N=30 1.18 0 (0-6.5)
Diary B Triad Mean Median (Range)	N=41 13.02 10.5 (0-44)	N=41 9.21 6.5 (0-29) *	N=30 15.5 14.75 (0-34.5)	N=30 8.53 5.25 (0-25) •	N=30 6.98 3.75 (0-45) ••1

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
✝ Significant between group difference at p<0.005
✝✝ Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects with the triad of social impairment

Presence of the triad of social impairment (Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS Triad Mean Median (Range)	N=6 41.5 40 (6-91)	N=6 57 59 (2-97)	N=8 26.63 25.5 (0-68)	N=8 22.38 16 (3-49)	N=8 22.63 23 (3-68)
PF Subject Triad Mean Median (Range)	N=41 53.05 60 (0-100)	N=41 54.51 50 (0-100)	N=31 69.84 80 (0-100)	N=31 68.55 85 (0-100)	N=31 65.32 65 (0-100)
RP Subject Triad Mean Median (Range)	N=40 70 100 (0-100)	N=40 80 100 (0-100)	N=30 80.83 100 (0-100)	N=30 86.67 100 (0-100) +Pre	N=30 80 100 (0-100)
BP Subject Triad Mean Median (Range)	N=40 72.5 73 (0-100)	N=40 77.78 84 (0-100)	N=27 82.81 100 (0-100)	N=27 76.91 84 (2.5-100)	N=27 77.17 84 (2.5-100)
GH Subject Triad Mean Median (Range)	N=30 57.13 62 (5-97)	N=30 61.37 67 (5-100)	N=27 71.07 77 (25-97) +	N=27 66.59 72 (20-100)	N=27 68.99 72 (30-100)
VT Subject Triad Mean Median (Range)	N=31 52.58 50 (10-95)	N=31 60.48 65 (5-85) *	N=27 62.04 60 (35-95)	N=27 61.30 65 (20-85)	N=27 65.37 65 (5-100)
SF Subject Triad Mean Median (Range)	N=41 74.09 75 (0-100)	N=41 82.32 100 (0-100)	N=30 79.58 87.5 (25-100)	N=30 75.42 81.25 (25-100)	N=30 88.33 100 (0-100) *2
RE Subject Triad Mean Median (Range)	N=39 75.21 100 (0-100)	N=39 87.18 100 (0-100)	N=26 84.62 100 (0-100)	N=26 79.49 100 (0-100)	N=26 78.21 100 (0-100)
MH Subject Triad Mean Median (Range)	N=31 67.87 68 (32-96)	N=31 73.94 72 (48-96) *	N=27 73.04 76 (32-96)	N=27 72.44 76 (40-96)	N=27 73.63 76 (8-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects with the triad of social impairment

Presence of the triad of social impairment (Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise Triad Mean Median (Range)	N=10 8.1 7.75 (4-12)	N=10 8.25 9 (2.5-13)	N=8 6.63 6.5 (0-14)	N=8 5.63 5 (0-13)	N=8 6 5.25 (0-13)
Carer Index Triad Mean Median (Range)	N=10 6.6 5.5 (2-13)	N=10 5.5 5 (2-11)	N=8 6 5.5 (1-13)	N=8 6 5.5 (1-13)	N=8 5.25 4.5 (1-12)
Emot Ex Freq Triad Mean Median (Range)	N=5 12.82 10 (10-21.4)	N=5 23.99 20.7 (14.67-32)	N=4 11.93 10.5 (6-20.7)	N=4 9.53 9.4 (6.3-13) +Post	N=4 17.95 17.7 (11-25.4)
Emot Ex Inten Triad Mean Median (Range)	N=5 15.95 13.7 (13.67-19.7)	N=5 27.83 29.4 (17.67-36) *	N=4 14.68 14.35 (5-25)	N=4 17.85 17.2 (10.6-26.4) +Post	N=4 24.6 23.5 (14-37.4)
Depers Freq Triad Mean Median (Range)	N=5 5.54 8.0 (0-8.4)	N=5 4.87 5.0 (1.67-7)	N=4 2.75 3.0 (0.7-4.3)	N=4 0.75 0.5 (0-2) +Post	N=4 1.68 0.65 (0-5.4)
Depers Inten Triad Mean Median (Range)	N=5 5.48 8.0 (0-8.4)	N=5 6.35 5.0 (3.7-12.7)	N=4 6.08 5.85 (4-8.6)	N=4 3.5 1.0 (0-12)	N=4 3.43 3.85 (0-6)
Pers Acc Freq Triad Mean Median (Range)	N=5 36.75 36.4 (36-38.7)	N=5 34.84 35.0 (31.7-37.4)	N=4 37.92 37.8 (32.4-43.7)	N=4 39.85 39.65 (36.4-43.7) +Post	N=4 37.63 36.9 (35.3-41.4)
Pers Acc Inten Triad Mean Median (Range)	N=5 34.88 33.7 (33-38)	N=5 35.84 37.0 (32-38.4)	N=4 40.43 40.0 (34-47.7)	N=4 39.0 39.5 (36.3-40.7) +Pre	N=4 38.8 39.0 (33.7-43.5)

* Significant within group change at $p<0.05$	+ Significant between group difference at $p<0.05$
** Significant within group change at $p<0.01$	++ Significant between group difference at $p<0.01$
• Significant within group change at $p<0.005$	† Significant between group difference at $p<0.005$
•• Significant within group change at $p<0.001$	†† Significant between group difference at $p<0.001$

SF-36 scores for the carers of subjects with the triad of social impairment

Presence of the triad of social impairment (Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer Triad Mean Median (Range)	N=20 70.75 82.5 (5-100)	N=20 72.25 80 (0-100)	N=22 77.05 90 (10-100)	N=22 83.86 92.5 (15-100) '	N=22 82.73 92.5 (5-100)
RP Carer Triad Mean Median (Range)	N=20 58.75 75 (0-100)	N=20 66.25 75 (0-100)	N=22 67.05 100 (0-100)	N=22 75.0 100 (0-100)	N=22 78.41 100 (0-100)
BP Carer Triad Mean Median (Range)	N=20 53.85 41.5 (12-100)	N=20 58.55 61.5 (0-100)	N=22 63.64 62 (0-100)	N=22 73.05 77 (0-100) +Pre	N=22 72.86 84 (0-100)
GH Carer Triad Mean Median (Range)	N=20 59.65 57.5 (20-100)	N=20 57.25 58.5 (12-100)	N=21 57.71 57 (0-100)	N=21 68.90 77 (30-100)	N=21 68.24 72 (10-100) '1
VT Carer Triad Mean Median (Range)	N=20 57.5 55 (5-90)	N=20 50.5 50 (0-80)	N=21 56.67 55 (10-95)	N=21 56.67 60 (20-90)	N=21 58.33 60 (10-90)
SF Carer Triad Mean Median (Range)	N=20 76.88 93.75 (0-100)	N=20 75 87.5 (0-100)	N=22 70.45 81.25 (12.5-100)	N=22 73.86 75 (25-100)	N=22 76.14 81.25 (25-100)
RE Carer Triad Mean Median (Range)	N=18 74.07 100 (0-100)	N=18 79.63 100 (0-100)	N=19 71.93 100 (0-100)	N=19 63.16 66.67 (0-100)	N=19 84.21 100 (0-100) '2
MH Carer Triad Mean Median (Range)	N=20 71.2 78 (32-96)	N=20 70.2 76 (12-100)	N=20 69.0 68 (36-96)	N=20 68.8 68 (44-96)	N=20 71.8 76 (36-100)
MH Carer *Triad* *Mean* *Median* *(Range)*	*N=20* *71.2* *78* *(32-96)*	*N=20* *70.2* *76* *(12-100)*	*N=21* *66.67* *64* *(20-96)*	*N=21* *67.43* *68* *(40-96)*	*N=21* *72.57* *76* *(36-100)*

' Significant within group change at p<0.05
" Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 19.

Scores for subjects without the triad of social impairment and their carers

Scores for subjects without the triad of social impairment

No presence of the triad of social impairment (No Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS No Triad Mean Median (Range)	N=65 194.4 202 (31-290)	N=65 191.54 198 (43-301)	N=50 189.76 186 (35-284)	N=50 185.28 181.5 (14-304)	N=50 199.8 197.5 (36-296) ••1&2
PIMRA No Triad Mean Median (Range)	N=66 8.87 8 (1-30)	N=66 7.85 6.5 (0-36) *	N=50 9.2 8 (0-29)	N=50 8.42 6 (1-33)	N=50 7.94 8 (1-24)
ABC Tot No Triad Mean Median (Range)	N=65 14.69 10 (0-64)	N=65 14.95 8 (0-83)	N=49 14.41 9 (0-78)	N=49 16.08 8 (0-92)	N=49 13.76 8 (0-73)
ABC TN No Triad Mean Median (Range)	N=65 10.31 9 (0-32)	N=65 10.58 8 (0-41)	N=49 10.47 8 (0-42)	N=49 11.49 6 (0-52)	N=49 10.47 7 (0-41)
ABC T3s No Triad Mean Median (Range)	N=65 0.97 0 (0-14)	N=65 0.94 0 (0-15)	N=49 0.92 0 (0-9)	N=49 0.94 0 (0-13)	N=49 0.73 0 (0-15)
IPDL No Triad Mean Median (Range)	N=65 10.17 11 (0-26)	N=65 10.48 10 (0-25)	N=51 8.98 8 (0-25)	N=51 9.45 9 (0-26)	N=51 10.27 9 (0-24) *
Choice No Triad Mean Median (Range)	N=40 54.90 55.5 (32-72)	N=40 51.45 51.5 (38-74) •	N=13 51.62 55 (31-63)	N=13 52.54 52 (45-67)	N=13 50.84 55 (35-66)
ICI No Triad Mean Median (Range)	N=65 6.86 7 (2-12)	N=65 6.72 7 (2-13)	N=51 7.10 7 (2-12)	N=51 7.55 8 (3-12)+Post	N=51 7.20 7 (3-14)
ICI freq No Triad Mean Median (Range)	N=65 20.42 20 (2-43)	N=65 19.42 19 (2-45)	N=51 20.86 21 (2-41)	N=51 22.96 24 (4-34) *	N=51 21.53 22 (4-41)
Diary A No Triad Mean Median (Range)	N=63 1.21 0 (0-10)	N=63 0.83 0 (0-5)	N=49 1.31 0 (0-7)	N=49 0.72 0 (0-6) *	N=49 1.14 0 (0-9.5)
Diary B No Triad Mean Median (Range)	N=63 14.48 14 (0-36.5)	N=63 9.33 6 (0-37.5) ••	N=49 15.34 13 (0-41)	N=49 11.19 10 (0-37) • +Pre	N=49 8.85 6.5 (0-48) ••1 *2

* Significant within group change at $p<0.05$
** Significant within group change at $p<0.01$
• Significant within group change at $p<0.005$
•• Significant within group change at $p<0.001$

\+ Significant between group difference at $p<0.05$
++ Significant between group difference at $p<0.01$
† Significant between group difference at $p<0.005$
†† Significant between group difference at $p<0.001$

Epilepsy Outcome Scale and SF-36 scores for subjects without the triad of social impairment

No presence of the triad of social impairment (No Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS No Triad Mean Median (Range)	N=15 43.73 22 (1-125)	N=15 39.53 23 (0-123)	N=8 47.88 49.5 (0-103)	N=8 33 22 (1-139)	N=8 41.25 32 (0-103)
PF Subject No Triad Mean Median (Range)	N=63 55.57 70 (0-100)	N=63 57.38 65 (0-100)	N=50 59.10 67.5 (0-100)	N=50 60.10 70 (0-100)	N=50 55.3 57.5 (0-100) *2
RP Subject No Triad Mean Median (Range)	N=64 73.44 100 (0-100)	N=64 76.95 100 (0-100)	N=49 69.39 100 (0-100)	N=49 69.90 100 (0-100)	N=49 69.90 100 (0-100)
BP Subject No Triad Mean Median (Range)	N=64 74.62 84 (27.5-100)	N=64 77.06 84 (12-100)	N=49 70.45 72 (0-100)	N=49 79.31 84 (0-100) *	N=49 77.12 84 (10-100)
GH Subject No Triad Mean Median (Range)	N=61 59.67 57 (0-100)	N=61 58.69 62 (5-100)	N=42 60.29 57 (15-100)	N=42 62.57 67 (10-100)	N=42 66.14 68.5 (20-97)
VT Subject No Triad Mean Median (Range)	N=61 57.25 55 (5-100)	N=61 57.46 60 (5-90)	N=43 59.07 60 (5-100)	N=43 60.81 60 (10-100)	N=43 62.79 65 (10-95)
SF Subject No Triad Mean Median (Range)	N=64 80.08 93.75 (0-100)	N=64 78.71 93.75 (0-100)	N=50 74 81.25 (12.5-100)	N=50 78.5 100 (0-100)	N=50 80.25 87.5 (25-100)
RE Subject No Triad Mean Median (Range)	N=63 76.19 100 (0-100)	N=63 81.48 100 (0-100)	N=50 78.67 100 (0-100)	N=50 76.67 100 (0-100)	N=50 86 100 (0-100)
MH Subject No Triad Mean Median (Range)	N=61 68.43 72 (0-100)	N=61 76.52 80 (28-100) *	N=43 71.53 76 (16-100)	N=43 75.70 76 (12-100)	N=43 77.49 84 (28-100) •1

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects without the triad of social impairment

No presence of the triad of social impairment (No Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise No Triad	N=22	N=22	N=31	N=31	N=31
Mean	5.39	4.98	4.42	4.97	3.95
Median	5	4.75	4.5	4	4
(Range)	(0.5-15)	(0-16)	(0-15)	(0-14)	(0-8) *2
Carer Index No Triad	N=22	N=22	N=30	N=30	N=30
Mean	5.32	4.36	4.33	4.03	2.63
Median	4.5	3.5	4	4	2
(Range)	(0-11)	(0-12)	(0-13)	(0-11)	(0-9) *1 *2
Emot Ex Freq No Triad	N=7	N=7	N=0	N=0	N=0
Mean	9.37	14.38			
Median	10.67	12.5			
(Range)	(1.5-16)	(6-22)			
Emot Ex Inten No Triad	N=6	N=6	N=0	N=0	N=0
Mean	13.77	20.96			
Median	13.32	19.5			
(Range)	(7-22.5)	(13.7-32) *			
Depers Freq No Triad	N=7	N=7	N=0	N=0	N=0
Mean	2.13	1.9			
Median	1.33	0.7			
(Range)	(0.3-6)	(0-6.3)			
Depers Inten No Triad	N=6	N=6	N=0	N=0	N=0
Mean	3.76	3.37			
Median	3.42	3.17			
(Range)	(2.7-6)	(0-7.3)			
Pers Acc Freq No Triad	N=7	N=7	N=0	N=0	N=0
Mean	40.43	38.51			
Median	41.7	40.5			
(Range)	(33.0-45.5)	(28.67-46)			
Pers Acc Inten No Triad	N=5	N=5	N=0	N=0	N=0
Mean	40.7	41.14			
Median	41.0	42.7			
(Range)	(37-43)	(33-49)			

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects without the triad of social impairment

No presence of the triad of social impairment (No Triad)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer No Triad Mean Median (Range)	N=35 76.29 85 (5-100)	N=35 70.57 85 (15-100)	N=34 71.03 85 (0-100)	N=34 75.74 80 (0-100)	N=34 73.09 80 (0-100)
RP Carer No Triad Mean Median (Range)	N=36 68.89 100 (0-100)	N=36 63.19 100 (0-100)	N=34 64.71 100 (0-100)	N=34 67.65 100 (0-100)	N=34 79.41 100 (0-100) *1
BP Carer No Triad Mean Median (Range)	N=36 66.56 72 (0-100)	N=36 63.67 62 (22-100)	N=35 67 64 (0-100)	N=35 67.74 80 (0-100)	N=35 72.06 74 (12-100)
GH Carer No Triad Mean Median (Range)	N=35 63.6 67 (8-100)	N=35 60.43 62 (5-100)	N=32 59.88 67 (15-100)	N=32 62.59 66 (10-90)	N=32 67 68.5 (15-100) *1
VT Carer No Triad Mean Median (Range)	N=35 58.14 60 (5-100)	N=35 52.29 55 (0-95)	N=33 60 65 (10-100)	N=33 57.73 60 (5-90)	N=33 58.94 60 (20-95)
SF Carer No Triad Mean Median (Range)	N=36 83.68 100 (0-100)	N=36 75.69 100 (12.5-100)	N=34 77.94 87.5 (12.5-100)	N=34 73.90 75 (0-100) +Pre	N=34 84.93 100 (0-100) •2
RE Carer No Triad Mean Median (Range)	N=33 89.90 100 (0-100)	N=33 69.70 100 (0-100) *	N=31 78.49 100 (0-100)	N=31 80.65 100 (0-100)	N=31 82.80 100 (0-100)
MH Carer No Triad Mean Median (Range)	N=35 80 84 (32-100)	N=35 73.71 80 (4-100)	N=33 75.15 76 (52-96) +	N=33 72.73 76 (36-100) +Pre	N=33 76.97 76 (48-100)
MH Carer No Triad *Mean* *Median* *(Range)*	*N=35* *80* *84* *(32-100)*	*N=35* *73.71* *80* *(4-100)*	*N=33* *75.15* *76* *(52-96) +*	*N=33* *72.73* *76* *(36-100) +Pre*	*N=33* *76.97* *76* *(48-100)*

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 20.

Scores for subjects with challenging behaviour and their carers

Scores for subjects with challenging behaviour

Presence of challenging behaviour (CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS CB	N=17	N=17	N=14	N=14	N=14
Mean	123.12	115.35	145.21	146.21	158.79
Median	135	114	130.5	152.5	147.5
(Range)	(45-189)	(44-177)	(48-274)	(68-266)	(64-289)
PIMRA CB	N=17	N=17	N=14	N=14	N=14
Mean	15.47	14.06	17.79	16.57	14.36
Median	15	14	16	14.5	14
(Range)	(9-26)	(9-26)	(10-30)	(6-33)	(3-24)
ABC Tot CB	N=17	N=17	N=14	N=14	N=14
Mean	59.12	47.88	64.86	53.07	43.07
Median	59	49	63.5	47.5	43.5
(Range)	(39-87)	(9-104) *	(37-115)	(33-92)	(17-94) *1
ABC TN CB	N=17	N=17	N=14	N=14	N=14
Mean	29.71	27.53	33.43	32.64	26.64
Median	30	30	31.5	32	27
(Range)	(21-37)	(9-47)	(19-51)	(15-52)	(11-46)
ABC T3s CB	N=17	N=17	N=14	N=14	N=14
Mean	9.24	5.29	10.14	4.36	4.14
Median	8	3	8	3	2
(Range)	(2-18)	(0-20)	(0-24)	(0-13) ** ++Pre	(0-15) *
IPDL CB	N=17	N=17	N=14	N=14	N=14
Mean	6.82	5.71	8.64	9.43	9.64
Median	7	5	7	9.5	10
(Range)	(0-12)	(0-12)	(2-25)	(1-26)	(3-16) +
Choice CB	N=15	N=15	N=8	N=8	N=8
Mean	47.2	43.13	51.75	52.63	44.13
Median	47	42	52	53	44
(Range)	(37-59)	(35-53) *	(46-56)	(40-63) ++Post	(36-55) *1 *2
ICI CB	N=17	N=17	N=14	N=14	N=14
Mean	6.59	5.53	7.93	8	7.36
Median	7	5	7	8	7.5
(Range)	(2-10)	(3-11)	(5-12)	(5-11) †Post	(4-10) +
ICI freq CB	N=17	N=17	N=14	N=14	N=14
Mean	20.65	15.88	25.36	23.57	23.5
Median	20	17	26	22.5	25.5
(Range)	(6-36)	(3-35)	(9-35)	(17-38) †Post	(9-35) +
Diary A CB	N=17	N=17	N=14	N=14	N=14
Mean	3.09	1.21	2.04	0.61	1.82
Median	2.5	0.5	1	0	0
(Range)	(0-13)	(0-4.5) *	(0-7.5)	(0-4.5) * †Pre	(0-9.5)
Diary B CB	N=17	N=17	N=14	N=14	N=14
Mean	13.03	10.35	19.36	10.32	7.79
Median	10	8.5	19.25	9.5	4.75
(Range)	(0-38.5)	(0-26)	(4-34) +	(0-27) **	(0-27) **1

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects with challenging behaviour

Presence of challenging behaviour (CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS CB Mean Median (Range)	N=3 39.67 22 (6-91)	N=3 51.33 36 (21-97)	N=3 31.33 32 (19-43)	N=3 23.67 19 (3-49)	N=3 19 23 (8-26)
PF Subject CB Mean Median (Range)	N=17 56.47 55 (0-100)	N=17 58.53 70 (0-100)	N=14 59.64 65 (0-100)	N=14 66.79 72.5 (25-100)	N=14 79.29 87.5 (35-100) *1&2
RP Subject CB Mean Median (Range)	N=17 79.41 100 (25-100)	N=17 91.18 100 (25-100)	N=13 55.77 100 (0-100)	N=13 82.69 100 (25-100)	N=13 75 75 (0-100)
BP Subject CB Mean Median (Range)	N=17 72.47 74 (12-100)	N=17 79.71 74 (41-100)	N=13 65.92 64 (0-100)	N=13 64.12 62 (2.5-100)	N=13 69.46 74 (12-100)
GH Subject CB Mean Median (Range)	N=15 61.53 62 (5-100)	N=15 61.33 62 (5-100)	N=11 64.64 67 (25-97)	N=11 61.18 67 (20-82)	N=11 71.27 77 (30-92)
VT Subject CB Mean Median (Range)	N=15 55.67 55 (10-95)	N=15 58 60 (5-85)	N=10 53 50 (20-80)	N=10 55.5 62.5 (10-80)	N=10 64 70 (10-90)
SF Subject CB Mean Median (Range)	N=17 77.21 75 (12.5-100)	N=17 83.09 100 (12.5-100)	N=14 63.39 68.75 (12.5-100)	N=14 66.96 62.5 (25-100)	N=14 78.57 87.5 (25-100)
RE Subject CB Mean Median (Range)	N=17 90.20 100 (33.33-100)	N=17 84.31 100 (0-100)	N=11 48.48 66.67 (0-100) ++	N=11 60.61 66.67 (0-100) +Pre	N=11 84.85 100 (0-100)
MH Subject CB Mean Median (Range)	N=15 59.73 60 (24-80)	N=15 70.67 72 (48-84) •	N=10 57.6 60 (16-80)	N=10 61.2 66 (16-92)	N=10 62.8 62 (28-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects with challenging behaviour

Presence of challenging behaviour (CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise CB Mean Median (Range)	N=1 12 12 (12-12)	N=1 8 8 (8-8)	N=5 7.4 5 (4-14)	N=5 7.8 6 (2-13)	N=5 5.7 4.5 (1-13)
Carer Index CB Mean Median (Range)	N=1 13 13 (13-13)	N=1 11 11 (11-11)	N=5 8.6 9 (2-13)	N=5 8.2 10 (2-12)	N=5 4.8 3 (1-12)
Emot Ex Freq CB Mean Median (Range)	N=3 10.9 10 (10-12.7)	N=3 22.42 20.6 (14.67-32)	N=2 6.15 6.15 (6-6.3)	N=2 9.35 9.35 (6.3-12.4)	N=2 15.7 15.7 (11-20.4)
Emot Ex Inten CB Mean Median (Range)	N=3 15.46 13.7 (13.7-19)	N=3 27.69 29.4 (17.67-36)	N=2 9.5 9.5 (5-14)	N=2 18.5 18.5 (10.6-26.4)	N=2 20.85 20.85 (14-27.7)
Depers Freq CB Mean Median (Range)	N=3 3.77 3.3 (0-8)	N=3 4.56 5 (1.67-7)	N=2 2 2 (0.7-3.3)	N=2 0.5 0.5 (0-1)	N=2 2.7 2.7 (0-5.4)
Depers Inten CB Mean Median (Range)	N=3 3.67 3 (0-8)	N=3 7.68 5.33 (5-12.7)	N=2 7.5 7.5 (6.4-8.6)	N=2 6 6 (0-12)	N=2 6 6 (6-6)
Pers Acc Freq CB Mean Median (Range)	N=3 37.12 36.67 (36-38.7)	N=3 35.03 35 (32.7-37.4)	N=2 40.65 40.65 (37.6-43.7)	N=2 42.5 42.5 (41.3-43.7)	N=2 38.85 38.85 (36.3-41.4)
Pers Acc Inten CB Mean Median (Range)	N=3 35.9 36 (33.7-38)	N=3 36.27 37 (33.4-38.4)	N=2 45.65 45.65 (43.6-47.7)	N=2 37.65 37.65 (36.3-39)	N=2 39 39 (39-39)

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

SF-36 scores for the carers of subjects with challenging behaviour

Presence of challenging behaviour (CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	92.14	95	77	79.5	79
Median	100	100	95	95	95
(Range)	(65-100)	(85-100)	(10-100)	(15-100)	(5-100)
RP Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	89.29	89.29	57.5	62.5	70
Median	100	100	62.5	100	100
(Range)	(25-100)	(50-100)	(0-100)	(0-100)	(0-100)
BP Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	86.29	87.43	58.4	73.5	73
Median	100	84	62.5	79	84
(Range)	(62-100)	(72-100)	(0-100)	(0-100)	(0-100)
GH Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	83.14	82.14	59.4	70.9	72.5
Median	87	77	72	78.5	83.5
(Range)	(62-100)	(57-100)	(0-97)	(30-87)	(10-100) *1
VT Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	71.43	63.57	54.5	50	62
Median	75	75	55	50	72.5
(Range)	(45-90)	(30-85)	(15-90)	(20-80) +Pre	(25-90) *2
SF Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	87.5	83.93	70	77.5	73.75
Median	100	100	93.7	75	87.5
(Range)	(50-100)	(25-100)	(12.5-100)	(50-100)	(25-100)
RE Carer CB	N=7	N=7	N=8	N=8	N=8
Mean	85.71	85.71	62.5	50	79.17
Median	100	100	83.33	66.67	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100) +Pre	(0-100) *2
MH Carer CB	N=7	N=7	N=10	N=10	N=10
Mean	77.71	79.43	72.8	70.8	74.8
Median	80	92	72	70	74
(Range)	(52-96)	(36-100)	(56-96)	(48-96)	(36-100)
MH Carer CB	*N=7*	*N=7*	*N=10*	*N=10*	*N=10*
Mean	*77.71*	*79.43*	*72.8*	*70.8*	*74.8*
Median	*80*	*92*	*72*	*70*	*74*
(Range)	*(52-96)*	*(36-100)*	*(56-96)*	*(48-96)*	*(36-100)*

*	Significant within group change at $p<0.05$
**	Significant within group change at $p<0.01$
•	Significant within group change at $p<0.005$
••	Significant within group change at $p<0.001$
+	Significant between group difference at $p<0.05$
++	Significant between group difference at $p<0.01$
†	Significant between group difference at $p<0.005$
††	Significant between group difference at $p<0.001$

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 21.

Scores for subjects without challenging behaviour and their carers

Scores for subjects without challenging behaviour

No Presence of challenging behaviour (No CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS No CB Mean Median (Range)	N=88 173.77 191 (31-290)	N=88 172.53 178 (17-301)	N=66 171.97 168.5 (35-284)	N=66 171.80 175.5 (14-304)	N=66 181.67 188.5 (36-296) ••1 •2
PIMRA No CB Mean Median (Range)	N=89 9.54 9 (1-30)	N=89 8.71 7 (0-36)	N=66 10.23 9.5 (0-25)	N=66 8.83 8 (0-32) *	N=66 8.80 8.5 (1-25) *1
ABC Tot No CB Mean Median (Range)	N=87 15.45 12 (0-53)	N=87 16.54 9 (0-79)	N=66 15.05 12.5 (0-56)	N=66 18.05 12.5 (0-71)	N=66 15.03 10 (0-62)
ABC TN No CB Mean Median (Range)	N=87 11.56 10 (0-46)	N=87 11.77 8 (0-49)	N=66 11.98 10.5 (0-34)	N=66 13.33 10 (0-44)	N=66 11.86 9.5 (0-43)
ABC T3s No CB Mean Median (Range)	N=87 0.70 0 (0-7)	N=87 0.97 0 (0-9)	N=66 0.35 0 (0-4)	N=66 0.85 0 (0-7) **	N=66 0.64 0 (0-7)
IPDL No CB Mean Median (Range)	N=88 9.03 9 (0-26)	N=88 9.31 9 (0-25)	N=68 8.46 8 (0-24)	N=68 8.72 9 (0-24)	N=68 9.68 9 (0-24) *1 *2
Choice No CB Mean Median (Range)	N=52 53.40 54 (32-72)	N=52 50.60 49.5 (38-74) **	N=24 50.21 50.5 (31-63)	N=24 53.29 52.5 (43-67)	N=24 48.96 50 (35-66) *2
ICI No CB Mean Median (Range)	N=88 6.35 6 (0-12)	N=88 6.35 7 (0-13)	N=68 6.93 7 (2-12)	N=68 7.40 7.5 (3-12) * ++Pre +Post	N=68 6.88 6.5 (3-14) *2
ICI freq No CB Mean Median (Range)	N=88 18.98 19 (0-43)	N=88 18.19 18.5 (0-45)	N=68 20.31 20.5 (2-41)	N=68 22.75 23 (4-36) • †Pre †Post	N=68 20.66 20.5 (4-41) *2
Diary A No CB Mean Median (Range)	N=87 1.48 0 (0-10)	N=87 0.74 0 (0-5) •	N=65 1.52 0 (0-18)	N=65 1.02 0 (0-6.5)	N=65 1.02 0 (0-9)
Diary B No CB Mean Median (Range)	N=87 14.07 13.5 (0-44)	N=87 9.07 6 (0-37.5) ••	N=65 14.55 12.5 (0-41)	N=65 10.15 8.5 (0-37) • +Pre	N=65 8.22 5 (0-48) ••1 *2

*	Significant within group change at p<0.05
**	Significant within group change at p<0.01
•	Significant within group change at p<0.005
••	Significant within group change at p<0.001

+	Significant between group difference at p<0.05
++	Significant between group difference at p<0.01
†	Significant between group difference at p<0.005
††	Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects without challenging behaviour

No Presence of challenging behaviour (No CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS No CB	N=18	N=18	N=13	N=13	N=13
Mean	43.67	43.39	38.62	28.62	34.92
Median	30	31.5	33	20	23
(Range)	(1-125)	(0-123)	(0-103)	(1-139)	(0-103)
PF Subject No CB	N=87	N=87	N=67	N=67	N=67
Mean	54.21	55.80	63.96	62.61	54.93
Median	70	55	75	70	60
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100) **1 •2
RP Subject No CB	N=87	N=87	N=66	N=66	N=66
Mean	70.69	75.57	77.27	75	73.48
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
BP Subject No CB	N=87	N=87	N=63	N=63	N=63
Mean	74.06	76.87	76.68	81.41	78.72
Median	84	84	84	100	84
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(2.5-100)
GH Subject No CB	N=76	N=76	N=58	N=58	N=58
Mean	58.30	59.22	64.48	64.71	66.49
Median	62	67	67	67	68.5
(Range)	(0-100)	(5-100)	(15-100)	(10-100)	(20-100)
VT Subject No CB	N=77	N=77	N=60	N=60	N=60
Mean	55.68	58.57	61.42	61.92	63.75
Median	55	60	60	62.5	65
(Range)	(5-100)	(5-90)	(5-100)	(20-100)	(5-100)
SF Subject No CB	N=88	N=88	N=66	N=66	N=66
Mean	77.84	79.55	78.79	79.55	84.28
Median	87.5	100	87.5	100	100
(Range)	(0-100)	(0-100)	(12.5-100)	(0-100)	(0-100)
RE Subject No CB	N=85	N=85	N=65	N=65	N=65
Mean	72.94	83.53	86.15	80.51	83.08
Median	100	100	100	100	100
(Range)	(0-100)	(0-100) *	(0-100) ++	(0-100)	(0-100)
MH Subject No CB	N=77	N=77	N=60	N=60	N=60
Mean	69.90	76.62	74.53	76.65	78.2
Median	76	80	76	76	84
(Range)	(0-100)	(28-100) *	(40-100)	(12-100)	(8-100) *1

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects without challenging behaviour

No Presence of challenging behaviour (No CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise No CB Mean Median (Range)	N=31 6.05 6 (0.5-15)	N=13 5.94 6 (0-16)	N=34 4.5 4.5 (0-15)	N=34 4.71 4 (0-14)	N=34 4.18 4 (0-10.5) +
Carer Index No CB Mean Median (Range)	N=31 5.48 5 (0-12)	N=31 4.52 4 (0-12) *	N=33 4.09 4 (0-13)	N=33 3.70 3 (0-11)	N=33 2.85 2 (0-10) + **1 *2
Emot Ex Freq No CB Mean Median (Range)	N=9 10.77 10.67 (1.5-21.4)	N=9 17.04 17 (6-32)	N=2 17.7 17.7 (14.7-20.7)	N=2 9.7 9.7 (6.4-13)	N=2 20.2 20.2 (15-25.4)
Emot Ex Inten No CB Mean Median (Range)	N=8 14.5 14.5 (7-22.5)	N=8 22.73 21.02 (13.7-32) *	N=2 19.85 19.85 (14.7-25)	N=2 17.2 17.2 (17-17.4)	N=2 28.35 28.35 (19.3-37.4)
Depers Freq No CB Mean Median (Range)	N=9 3.48 1.5 (0.3-8.4)	N=9 2.67 1 (0-6.3)	N=2 3.5 3.5 (2.7-4.3)	N=2 1 1 (0-2)	N=2 0.65 0.65 (0-1.3)
Depers Inten No CB Mean Median (Range)	N=8 4.87 3.6 (2.7-8.4)	N=8 3.62 4.35 (0-7.3)	N=2 4.65 4.65 (4-5.3)	N=2 1 1 (0-2) +Pre	N=2 0.85 0.85 (0-1.7)
Pers Acc Freq No CB Mean Median (Range)	N=9 39.49 38.33 (33-45.5)	N=9 37.63 37.4 (28.67-46)	N=2 35.2 35.2 (32.4-38)	N=2 37.2 37.2 (36.4-38)	N=2 36.4 36.4 (35.3-37.5)
Pers Acc Inten No CB Mean Median (Range)	N=7 38.6 40.5 (33-43)	N=7 39.44 38.4 (32-49)	N=2 35.2 35.2 (34-36.4)	N=2 40.35 40.35 (40-40.7)	N=2 38.6 38.6 (33.7-43.5)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects without challenging behaviour

No Presence of challenging behaviour (No CB)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer No CB	N=48	N=48	N=46	N=46	N=46
Mean	71.67	67.71	72.61	78.80	76.41
Median	82.5	77.5	85	87.5	87.5
(Range)	(5-100)	(0-100)	(0-100)	(0-100)	(0-100)
RP Carer No CB	N=49	N=49	N=46	N=46	N=46
Mean	61.84	60.71	67.39	72.28	80.98
Median	80	75	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100) + *1
BP Carer No CB	N=49	N=49	N=47	N=47	N=47
Mean	58.55	58.18	67.26	69	72.23
Median	51	52	64	80	74
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(12-100) +
GH Carer No CB	N=48	N=48	N=43	N=43	N=43
Mean	59.10	55.94	58.93	63.74	66.33
Median	62	57.5	65	67	67
(Range)	(8-100)	(5-97)	(10-100)	(10-100)	(15-100) *1
VT Carer No CB	N=48	N=48	N=44	N=44	N=44
Mean	55.94	49.90	59.66	58.98	57.95
Median	55	50	65	60	60
(Range)	(5-100)	(0-95)	(10-100)	(5-90)	(10-95)
SF Carer No CB	N=49	N=49	N=46	N=46	N=46
Mean	80.36	74.23	76.09	73.10	83.15
Median	100	87.5	81.25	75	93.75
(Range)	(0-100)	(0-100)	(12.5-100)	(0-100) +Pre	(0-100) **2
RE Carer No CB	N=44	N=44	N=42	N=42	N=42
Mean	84.09	71.21	78.57	78.57	84.13
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
MH Carer No CB	N=48	N=48	N=43	N=43	N=43
Mean	76.67	71.42	72.84	71.35	75.07
Median	82	76	76	72	76
(Range)	(32-100)	(4-100)	(36-96)	(36-100)	(36-100)
MH Carer No CB	*N=48*	*N=48*	*N=44*	*N=44*	*N=44*
Mean	*76.67*	*71.42*	*71.64*	*70.64*	*75.36*
Median	*82*	*76*	*76*	*72*	*76*
(Range)	*(32-100)*	*(4-100)*	*(20-96)*	*(36-100) +Pre*	*(36-100)*

*	Significant within group change at $p<0.05$	+	Significant between group difference at $p<0.05$
**	Significant within group change at $p<0.01$	++	Significant between group difference at $p<0.01$
•	Significant within group change at $p<0.005$	†	Significant between group difference at $p<0.005$
••	Significant within group change at $p<0.001$	††	Significant between group difference at $p<0.001$

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 22.

Scores for subjects with an indication of mental illness and their carers

Scores for subjects with an indication of mental illness

Indication of mental illness (MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS MI Mean Median (Range)	N=43 163.86 165 (40-290)	N=43 161.05 164 (17-295)	N=38 162.37 159 (45-284)	N=38 163.55 173.5 (38-304)	N=38 174.16 183.5 (36-295) •1 **2
PIMRA MI Mean Median (Range)	N=43 15.70 15 (7-30)	N=43 13.60 13 (4-36) *	N=37 16.46 16 (7-30)	N=37 13.89 13 (3-33) • +Pre	N=37 12.59 13 (3-24) ••1
ABC Tot MI Mean Median (Range)	N=40 33.75 33 (0-87)	N=40 29.05 19.5 (0-104)	N=36 33.92 29.5 (0-115)	N=36 32.72 32.5 (0-92)	N=36 27.64 19.5 (0-94)
ABC TN MI Mean Median (Range)	N=40 19.95 21.5 (0-46)	N=40 18.73 17 (0-49)	N=36 20.78 19.5 (0-51)	N=36 20.94 18 (0-52)	N=36 18.72 15 (0-46)
ABC T3s MI Mean Median (Range)	N=40 3.65 1.5 (0-18)	N=40 2.23 0 (0-20)	N=36 3.64 0.5 (0-24)	N=36 2.33 0.5 (0-13)	N=36 2.08 0 (0-15)
IPDL MI Mean Median (Range)	N=42 8.81 8 (0-23)	N=42 9 8.5 (0-25)	N=39 8.74 7 (0-25)	N=39 9.23 10 (0-26)	N=39 9.77 10 (0-24) *1
Stancliff MI Mean Median (Range)	N=25 51.4 50 (37-72)	N=25 47.56 45 (35-74)	N=19 48 49 (31-56)	N=19 52.47 53 (40-63) * +Post	N=19 45.26 45 (35-56) •
ICI MI Mean Median (Range)	N=42 6.05 6 (0-11)	N=42 5.64 5 (0-12)	N=39 7 7 (2-12)	N=39 7.15 7 (3-12) ++Post	N=39 6.77 7 (3-11) +
ICI freq MI Mean Median (Range)	N=42 18.31 19.5 (0-39)	N=42 17.17 17.5 (0-45)	N=39 20.74 21 (5-35)	N=39 22 22 (4-38) +Post	N=39 20.79 22 (4-35)
Diary A MI Mean Median (Range)	N=42 2 0 (0-13)	N=42 0.58 0 (0-4.5) •	N=38 2.07 0 (0-18)	N=38 1.11 0 (0-6.5)	N=38 1.32 0 (0-9.5)
Diary B MI Mean Median (Range)	N=42 13.51 10.5 (0-44)	N=42 10.25 7.75 (0-37.5) *	N=38 17.76 18.25 (0-41)	N=38 10.47 8.5 (0-37) ••	N=38 8.12 3.25 (0-48) ••1

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects with an indication of mental illness

Indication of mental illness (MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS MI	N=10	N=10	N=10	N=10	N=10
Mean	50.6	46.8	24.2	19.6	22.4
Median	41.5	37.5	18.5	12	23
(Range)	(6-112)	(2-109)	(0-68)	(1-49) + Pre	(2-68)
PF Subject MI	N=43	N=43	N=39	N=39	N=39
Mean	58.26	58.95	63.59	65.51	61.79
Median	70	65	75	85	70
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
RP Subject MI	N=42	N=42	N=38	N=38	N=38
Mean	64.88	77.38	70.39	73.68	77.63
Median	75	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
BP Subject MI	N=42	N=42	N=36	N=36	N=36
Mean	68.48	77.71	71.86	76.33	72.89
Median	68	84	74	84	84
(Range)	(12-100)	(0-100) *	(0-100)	(0-100)	(10-100)
GH Subject MI	N=33	N=33	N=34	N=34	N=34
Mean	51.64	57.03	64	62.71	66.25
Median	52	62	64.5	67	74.5
(Range)	(0-100)	(5-100)	(15-97)	(15-100)	(25-100)
VT Subject MI	N=34	N=34	N=33	N=33	N=33
Mean	46.76	55.29	56.82	56.67	62.12
Median	45	52.5	55	60	65
(Range)	(5-95)	(5-90) *	(20-95)	(10-85) +Pre	(10-100) *
SF Subject MI	N=43	N=43	N=39	N=39	N=39
Mean	70.64	76.45	69.87	71.79	78.53
Median	75	87.5	75	75	87.5
(Range)	(0-100)	(0-100)	(12.5-100)	(0-100)	(25-100)
RE Subject MI	N=41	N=41	N=35	N=35	N=35
Mean	64.23	80.49	68.57	67.62	78.10
Median	66.67	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
MH Subject MI	N=34	N=34	N=33	N=33	N=33
Mean	54.24	68.71	63.64	66.42	69.09
Median	52	70	64	72	68
(Range)	(0-96)	(28-100) ●	(16-96) +	(12-96) ++Pre	(28-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
●	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
●●	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects with an indication of mental illness

Indication of mental illness (MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise MI Mean Median (Range)	N=12 6.04 5.5 (1.5-12)	N=12 6.29 6.5 (2.5-10)	N=13 5.08 5 (0-9.5)	N=13 5.85 5.5 (0-12)	N=13 4.31 4 (0-10.5) *2
Carer Index MI Mean Median (Range)	N=12 6.42 6.5 (1-13)	N=12 5.67 5.5 (2-11)	N=13 4.62 2 (0-13)	N=13 4.85 4 (1-11)	N=13 2.15 1 (0-10) **2 =
Emot Ex Freq MI Mean Median (Range)	N=5 13.09 10.7 (10-21.4)	N=5 21.93 20.6 (17-32)	N=3 11 6.3 (6-20.7)	N=3 8.37 6.4 (6.3-12.4) +Post	N=3 18.93 20.4 (11-25.4)
Emot Ex Inten MI Mean Median (Range)	N=5 15.81 15.3 (11.33-19.7)	N=5 26.63 26.7 (18.7-36) *	N=3 14.67 14 (5-25)	N=3 18.13 17.4 (10.6-26.4)	N=3 26.37 27.7 (14-37.4)
Depers Freq MI Mean Median (Range)	N=5 4.41 3.3 (1-8.4)	N=5 3.88 5 (0.7-7)	N=3 2.23 2.7 (0.7-3.3)	N=3 0.33 0 (0-1) +Pre	N=3 1.8 0 (0-5.4)
Depers Inten MI Mean Median (Range)	N=5 5.29 3.7 (3-8.4)	N=5 4.81 3.7 (1.3-12.7)	N=3 6.33 6.4 (4-8.6)	N=3 4 0 (0-12)	N=3 4 6 (0-6)
Pers Acc Freq MI Mean Median (Range)	N=5 37.49 38 (36-38.7)	N=5 33.09 32.7 (28.67-37.4)	N=3 37.9 37.6 (32.4-43.7)	N=3 40.47 41.3 (36.4-43.7)	N=3 38.4 37.5 (36.3-41.4)
Pers Acc Inten MI Mean Median (Range)	N=5 36.74 37 (33-42)	N=5 34.76 33.4 (32-38.4)	N=3 42.57 43.6 (36.4-47.7)	N=3 38.67 39 (36.3-40.7)	N=3 40.5 39 (39-43.5) +

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects with an indication of mental illness

Indication of mental illness (MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer MI Mean Median (Range)	N=23 76.96 90 (5-100)	N=23 75.22 90 (15-100)	N=25 71 80 (0-100)	N=25 82.2 95 (30-100) *	N=25 81 95 (30-100)
RP Carer MI Mean Median (Range)	N=23 70.65 100 (0-100)	N=23 71.74 100 (0-100)	N=25 71 100 (0-100)	N=25 77 100 (0-100)	N=25 79 100 (0-100)
BP Carer MI Mean Median (Range)	N=23 64.22 62 (22-100)	N=23 59.70 62 (22-100)	N=25 69.4 72 (0-100)	N=25 76.44 84 (22-100) +Post	N=25 81.12 84 (22-100) * =
GH Carer MI Mean Median (Range)	N=22 65.73 69.5 (25-100)	N=22 59.64 64.5 (15-100)	N=24 62.75 72 (10-97)	N=24 71.46 77 (25-100)	N=24 71.54 74.5 (25-100) *1
VT Carer MI Mean Median (Range)	N=22 61.14 60 (25-100)	N=22 50.68 50 (0-95)	N=24 60 62.5 (10-95)	N=24 60 60 (35-90)	N=24 62.5 70 (10-90)
SF Carer MI Mean Median (Range)	N=23 87.5 100 (50-100)	N=23 71.74 87.5 (12.5-100) *	N=25 82.5 100 (25-100)	N=25 82.5 87.5 (25-100)	N=25 82 87.5 (25-100)
RE Carer MI Mean Median (Range)	N=22 83.33 100 (0-100)	N=22 75.76 100 (0-100)	N=23 75.36 100 (0-100)	N=23 78.26 100 (0-100)	N=23 82.61 100 (0-100)
MH Carer MI Mean Median (Range)	N=22 75.64 82 (32-96)	N=22 68.18 72 (4-100)	N=24 70.17 72 (36-96)	N=24 72.33 72 (44-96)	N=24 75.17 76 (36-100)
MH Carer MI *Mean* *Median* *(Range)*	*N=22* *75.64* *82* *(32-96)*	*N=22* *68.18* *72* *(4-100)*	*N=24* *70.17* *72* *(36-96)*	*N=24* *72.33* *72* *(44-96)*	*N=24* *75.17* *76* *(36-100)*

*	Significant within group change at $p<0.05$	+	Significant between group difference at $p<0.05$
**	Significant within group change at $p<0.01$	++	Significant between group difference at $p<0.01$
●	Significant within group change at $p<0.005$	†	Significant between group difference at $p<0.005$
●●	Significant within group change at $p<0.001$	††	Significant between group difference at $p<0.001$

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 23.

Scores for subjects without an indication of mental illness and their carers

Scores for subjects without an indication of mental illness

No indication of mental illness (No MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS No MI	N=61	N=61	N=42	N=42	N=42
Mean	167.67	165.61	171.74	170.74	180.83
Median	182	164	168.5	173.5	181.5
(Range)	(31-285)	(43-301)	(35-278)	(14-278)	(36-296) •1 **2
PIMRA No MI	N=63	N=63	N=43	N=43	N=43
Mean	6.94	6.81	7.33	7	7.35
Median	6	6	8	6	6
(Range)	(1-16)	(0-31)	(0-16)	(0-24)	(1-25)
ABC Tot No MI	N=63	N=63	N=44	N=44	N=44
Mean	15.43	17.02	15.45	17.18	13.64
Median	11	8	10	9	8
(Range)	(0-83)	(0-83)	(0-79)	(0-65)	(0-55)
ABC TN No MI	N=63	N=63	N=44	N=44	N=44
Mean	11.03	11.49	11.61	13.25	10.95
Median	9	8	9.5	8.5	7.5
(Range)	(0-37)	(0-41)	(0-41)	(0-47)	(0-41)
ABC T3s No MI	N=63	N=63	N=44	N=44	N=44
Mean	1.13	1.35	0.77	0.75	0.57
Median	0	0	0	0	0
(Range)	(0-15)	(0-15)	(0-14)	(0-7)	(0-7)
IPDL No MI	N=63	N=63	N=43	N=43	N=43
Mean	8.59	8.54	8.26	8.49	9.58
Median	9	9	8	9	9
(Range)	(0-26)	(0-24)	(0-24)	(0-21)	(0-23)
Stancliff No MI	N=42	N=42	N=13	N=13	N=13
Mean	52.38	49.74	54.38	54.08	51.38
Median	53	49	53	52	53
(Range)	(32-71)	(38-71) •	(48-63)	(46-67)	(40-66)
ICI No MI	N=63	N=63	N=43	N=43	N=43
Mean	6.62	6.6	7.19	7.81	7.14
Median	7	7	7	8	7
(Range)	(2-12)	(1-13)	(2-12)	(4-12) * †Pre †Post	(3-14) *
ICI freq No MI	N=63	N=63	N=43	N=43	N=43
Mean	19.87	18.25	21.56	23.70	21.47
Median	19	19	21	24	21
(Range)	(4-43)	(2-40)	(2-41)	(9-34) * †Pre ††Post	(8-41)
Diary A No MI	N=61	N=61	N=41	N=41	N=41
Mean	1.55	0.93	1.20	0.79	1.01
Median	0.5	0.5	0	0	0
(Range)	(0-10)	(0-5) *	(0-6)	(0-4.5)	(0-9)
Diary B No MI	N=61	N=61	N=41	N=41	N=41
Mean	14.20	8.68	13.21	9.91	8.16
Median	14	6	11.5	9.5	5.5
(Range)	(0-38.5)	(0-29.5) ••	(0-40.5)	(0-36.5) * +Pre	(0-45) •1

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects without an indication of mental illness

No indication of mental illness (No MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS No MI	N=11	N=11	N=6	N=6	N=6
Mean	36.27	42.45	59	41.17	47.83
Median	18	24	49.5	25	38
(Range)	(1-125)	(0-123)	(24-103)	(2-139)	(0-103)
PF Subject No MI	N=60	N=60	N=42	N=42	N=42
Mean	52.68	54.42	62.86	61.31	56.67
Median	62.5	50	72.5	70	60
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
RP Subject No MI	N=61	N=61	N=41	N=41	N=41
Mean	76.64	79.10	76.83	78.66	70.12
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
BP Subject No MI	N=61	N=61	N=40	N=40	N=40
Mean	78.68	77.11	77.53	80.36	80.96
Median	84	84	86	92	84
(Range)	(27.5-100)	(12-100)	(0-100)	(2.5-100)	(2.5-100)
GH Subject No MI	N=58	N=58	N=35	N=35	N=35
Mean	62.93	61.02	65	65.54	68.23
Median	71	67	67	67	67
(Range)	(5-100)	(5-100)	(20-100)	(10-100)	(20-97)
VT Subject No MI	N=58	N=58	N=37	N=37	N=37
Mean	60.91	60.34	63.24	64.86	65.27
Median	60	60	60	65	65
(Range)	(20-100)	(5-90)	(5-100)	(25-100)	(5-95)
SF Subject No MI	N=61	N=61	N=41	N=41	N=41
Mean	83.61	82.99	82.01	82.62	87.80
Median	100	100	100	100	100
(Range)	(37.5-100)	(0-100)	(37.5-100)	(25-100)	(0-100)
RE Subject No MI	N=60	N=60	N=41	N=41	N=41
Mean	85	85.56	91.06	86.18	87.80
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
MH Subject No MI	N=58	N=58	N=37	N=37	N=37
Mean	76.45	79.72	79.68	81.59	82.16
Median	80	84	80	84	84
(Range)	(0-100)	(48-100)	(48-100)	(60-100)	(8-100)

*	Significant within group change at $p<0.05$	+	Significant between group difference at $p<0.05$
**	Significant within group change at $p<0.01$	++	Significant between group difference at $p<0.01$
•	Significant within group change at $p<0.005$	†	Significant between group difference at $p<0.005$
••	Significant within group change at $p<0.001$	††	Significant between group difference at $p<0.001$

Stress and burnout scores for the carers of subjects without an indication of mental illness

No indication of mental illness (No MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise No MI Mean Median (Range)	N=19 6.08 6 (0.5-15)	N=19 5.66 5 (0-16)	N=26 4.77 4.25 (0-15)	N=26 4.73 4 (0-14)	N=26 4.4 4 (0-13)
Carer Index No MI Mean Median (Range)	N=19 5.11 4 (0-12)	N=19 4 3 (0-12) *	N=25 4.72 4 (0-12)	N=25 4 4 (0-12)	N=25 3.6 3 (0-12) *1
Emot Ex Freq No MI Mean Median (Range)	N=7 9.17 10 (1.5-16)	N=7 15.85 12.5 (6-32)	N=1 14.7 14.7 (14.7-14.7)	N=1 13 13 (13-13)	N=1 15 15 (15-15)
Emot Ex Inten No MI Mean Median (Range)	N=6 13.90 13.69 (7-22.5)	N=6 21.96 19.5 (13.7-32) *	N=1 14.7 14.7 (14.7-14.7)	N=1 17 17 (17-17)	N=1 19.3 19.3 (19.3-19.3)
Depers Freq No MI Mean Median (Range)	N=7 2.94 1.5 (0-8)	N=7 2.61 1.67 (0-6.3)	N=1 4.3 4.3 (4.3-4.3)	N=1 2 2 (2-2)	N=1.3 1.3 (1.3-1.3)
Depers Inten No MI Mean Median (Range)	N=6 3.92 3.4 (0-8)	N=6 4.66 5.15 (0-7.3)	N=1 5.3 5.3 (5.3-5.3)	N=1 2 2 (2-2)	N=1.7 1.7 1.7 (1.7-1.7)
Pers Acc Freq No MI Mean Median (Range)	N=7 39.91 41.7 (33-45.5)	N=7 39.76 40.5 (34-46)	N=1 38 38 (38-38)	N=1 38 38 (38-38)	N=1 35.3 35.3 (35.3-35.3)
Pers Acc Inten No MI Mean Median (Range)	N=5 38.84 40.5 (33.7-43)	N=5 42.22 42.7 (37-49) *	N=1 34 34 (34-34)	N=1 40 40 (40-40)	N=1 33.7 33.7 (33.7-33.7)

* Significant within group change at $p<0.05$
** Significant within group change at $p<0.01$
● Significant within group change at $p<0.005$
●● Significant within group change at $p<0.001$

\+ Significant between group difference at $p<0.05$
++ Significant between group difference at $p<0.01$
† Significant between group difference at $p<0.005$
†† Significant between group difference at $p<0.001$

SF-36 scores for the carers of subjects without an indication of mental illness

No indication of mental illness (No MI)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer No MI Mean Median (Range)	N=31 72.10 80 (5-100)	N=31 68.39 85 (0-100)	N=31 75.32 85 (0-100)	N=31 76.29 85 (0-100)	N=31 73.55 85 (0-100)
RP Carer No MI Mean Median (Range)	N=32 62.66 90 (0-100)	N=32 60.94 75 (0-100)	N=31 61.29 100 (0-100)	N=31 65.32 100 (0-100)	N=31 79.03 100 (0-100) *1 *2
BP Carer No MI Mean Median (Range)	N=32 61.38 57 (0-100)	N=32 64.63 72 (0-100)	N=32 62.81 62 (0-100)	N=32 64.59 69 (0-100)	N=32 65.53 74 (0-100)
GH Carer No MI Mean Median (Range)	N=32 61.03 62 (8-100)	N=32 60.09 62 (5-100)	N=29 55.93 62 (0-100)	N=29 59.83 62 (10-90)	N=29 64.14 67 (10-100) *1
VT Carer No MI Mean Median (Range)	N=32 56.56 57.5 (5-95)	N=32 53.13 57.5 (0-85)	N=30 57.67 62.5 (10-100)	N=30 55.17 60 (5-85)	N=30 55.67 60 (20-95)
SF Carer No MI Mean Median (Range)	N=32 78.13 100 (0-100)	N=32 77.73 100 (0-100)	N=31 68.95 75 (12.5-100)	N=31 66.94 75 (0-100) +Pre	N=31 81.05 87.5 (0-100) *1 **2
RE Carer No MI Mean Median (Range)	N=28 88.10 100 (0-100)	N=28 72.62 100 (0-100)	N=27 76.54 100 (0-100)	N=27 70.37 100 (0-100)	N=27 83.95 100 (0-100) *2
MH Carer No MI Mean Median (Range)	N=32 78.13 82 (32-100)	N=32 76.5 84 (12-100)	N=29 75.03 80 (52-96)	N=29 70.34 72 (36-100) +Pre +Post	N=29 74.90 76 (36-100)
MH Carer No MI *Mean* *Median* *(Range)*	*N=32* *78.13* *82* *(32-100)*	*N=32* *76.5* *84* *(12-100)*	*N=30* *73.2* *78* *(20-96)*	*N=30* *69.33* *72* *(36-100)*	*N=30* *75.33* *76* *(36-100)*

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 24.

Scores for subjects who had no health needs identified at the health check and their carers

Scores for subjects who had no health needs identified at the health check

No health needs identified at health check (Healthy)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS Healthy Mean Median (Range)	N=43 168.02 165 (40-290)	N=43 166.19 151 (17-301)	N=42 167.62 164.5 (35-284)	N=42 168.98 170 (14-278)	N=42 181.90 192.5 (36-291) ••1&2
PIMRA Healthy Mean Median (Range)	N=43 8.93 8 (1-23)	N=43 8.37 8 (0-23)	N=43 12.16 12 (0-30) +	N=43 10.77 9 (2-33)	N=43 9.30 8 (1-24) •1
ABC Tot Healthy Mean Median (Range)	N=41 17.68 11 (0-83)	N=41 15.90 10 (0-63)	N=43 26.47 14 (0-115)	N=43 25.35 20 (0-83)	N=43 20.35 13 (0-94) *1
ABC TN Healthy Mean Median (Range)	N=41 11.95 9 (0-37)	N=41 11.12 9 (0-37)	N=43 16.26 13 (0-51)	N=43 16.95 15 (0-49)	N=43 13.86 11 (0-46)
ABC T3s Healthy Mean Median (Range)	N=41 1.46 0 (0-15)	N=41 1.0 0 (0-10)	N=43 2.98 0 (0-24)	N=43 1.74 0 (0-13)	N=43 1.63 0 (0-15)
IPDL Healthy Mean Median (Range)	N=42 9.12 9 (0-24)	N=42 10.38 10 (0-25)	N=43 8.30 7 (0-25)	N=43 9.47 9 (0-26) *	N=43 10.30 10 (0-23) •1
Stancliff Healthy Mean Median (Range)	N=28 51.11 51.5 (32-71)	N=28 48.96 48 (38-74)	N=16 50.56 50 (31-62)	N=16 53.88 53 (40-67) +Post	N=16 47.06 44 (35-66) •2
ICI Healthy Mean Median (Range)	N=42 6.12 6 (0-10)	N=42 6.45 7 (1-13)	N=43 7.42 7 (4-12) +	N=43 7.86 8 (3-12) •Pre ++Post	N=43 7.19 7 (3-13) *2
ICI freq Healthy Mean Median (Range)	N=42 18.64 20 (0-39)	N=42 18.05 17.5 (2-45)	N=43 21.98 21 (5-35)	N=43 23.58 23 (4-38) +Pre †Post	N=43 21.37 20 (4-35)
Diary A Healthy Mean Median (Range)	N=43 1.97 0.5 (0-10)	N=43 1.06 0.5 (0-5) *	N=41 2.03 1.5 (0-18)	N=41 0.59 0 (0-6) • †Pre +Post	N=41 1.22 0 (0-9.5) *2
Diary B Healthy Mean Median (Range)	N=43 16.40 17 (0-44)	N=43 10.31 8.5 (0-37.5) •	N=41 16.98 17 (0-39.5)	N=41 10.35 9 (0-36.5) •• +Pre	N=41 8.13 4 (0-42) ••1

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects who had no health needs identified at the health check

No health needs identified at health check (Healthy)	Group 1		Group 2		
	Pre	Post	Pre 1	Pre 2	Post
EOS Healthy Mean Median (Range)	N=11 48.91 21 (5-125)	N=11 31.91 24 (0-109)	N=11 41.45 32 (0-103)	N=11 32.64 24 (1-139)	N=11 34.82 23 (0-103)
PF Patient Healthy Mean Median (Range)	N=43 59.79 70 (0-100)	N=43 66.28 75 (0-100)	N=43 58.84 75 (0-100)	N=43 60.93 70 (0-100)	N=43 65 75 (0-100)
RP Patient Healthy Mean Median (Range)	N=43 75.58 100 (0-100)	N=43 84.30 100 (0-100)	N=42 63.69 87.5 (0-100)	N=42 72.02 100 (0-100)	N=42 77.38 100 (0-100)
BP Patient Healthy Mean Median (Range)	N=43 73.07 74 (0-100)	N=43 78.58 84 (22-100)	N=41 74.20 84 (0-100)	N=41 72.21 74 (0-100)	N=41 76.29 84 (12-100)
GH Patient Healthy Mean Median (Range)	N=37 58.56 62 (5-100)	N=37 63.59 67 (10-100)	N=34 60.44 61 (15-97)	N=34 61.94 67 (10-100)	N=34 68.43 71 (20-100) *1
VT Patient Healthy Mean Median (Range)	N=38 55.07 50 (10-100)	N=38 60.13 60 (20-90)	N=36 55.69 55 (5-100)	N=36 56.94 60 (10-90)	N=36 63.33 65 (10-100) *1&2
SF Patient Healthy Mean Median (Range)	N=44 80.40 93.75 (25-100)	N=44 84.94 100 (25-100)	N=41 74.70 75 (12.5-100)	N=41 74.09 75 (0-100)	N=41 81.40 87.5 (25-100)
RE Patient Healthy Mean Median (Range)	N=42 73.02 100 (0-100)	N=42 81.75 100 (0-100)	N=39 72.65 100 (0-100)	N=39 76.92 100 (0-100)	N=39 82.05 35.74 (0-100)
MH Patient Healthy Mean Median (Range)	N=38 68.79 72 (0-100)	N=38 75.58 78 (48-96)	N=36 68.67 74 (16-96)	N=36 71.89 76 (12-100)	N=36 73.44 72 (28-100)

*	Significant within group change at $p<0.05$	+	Significant between group difference at $p<0.05$
**	Significant within group change at $p<0.01$	++	Significant between group difference at $p<0.01$
•	Significant within group change at $p<0.005$	†	Significant between group difference at $p<0.005$
••	Significant within group change at $p<0.001$	††	Significant between group difference at $p<0.001$

Stress and burnout scores for the carers of subjects who had no health needs identified at the health check

No health needs identified at health check (Healthy)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise Healthy Mean Median (Range)	N=12 6.46 6 (1.5-15)	N=12 6.04 6.5 (0-13)	N=23 5 5 (0-14)	N=23 5.20 4 (0-13)	N=23 3.91 3 (0-13) **2 +
Carer Index Healthy Mean Median (Range)	N=12 5.92 5.5 (0-11)	N=12 4.17 4.5 (0-8) *	N=23 5.09 5 (0-13)	N=23 4.61 4 (0-12)	N=23 3 2 (0-12) *1
Emot Ex Freq Healthy Mean Median (Range)	N=1 10 10 (10-10)	N=1 14.67 14.67 (14.67-14.67)	N=3 11 6.3 (6-20)	N=3 8.37 6.4 (6.3-12.4)	N=3 18.93 20.4 (11-25.4)
Emot Ex Inten Healthy Mean Median (Range)	N=1 13.67 13.67 (13.67-13.67)	N=1 17.67 17.67 (17.67-17.67)	N=3 14.66 14 (5-25)	N=3 18.13 17.4 (10.60-26.4)	N=3 26.37 27.7 (14-37.4)
Depers Freq Healthy Mean Median (Range)	N=1 0 0 (0-0)	N=1 1.67 1.67 (1.67-1.67)	N=3 2.23 2.7 (0.7-3.3)	N=3 0.33 0 (0-1)	N=3 1.8 0 (0-5.4)
Depers Inten Healthy Mean Median (Range)	N=1 0 0 (0-0)	N=1 5.33 5.33 (5.33-5.33)	N=3 6.33 6.4 (4-8.6)	N=3 4 0 (0-12)	N=3 4 6 (0-6)
Pers Acc Freq Healthy Mean Median (Range)	N=1 36.67 36.67 (36.7-36.7)	N=1 35 35 (35-35)	N=3 37.9 37.6 (32.4-43.7)	N=3 40.47 41.3 (36.4-43.7)	N=3 38.4 37.5 (36.3-41.4)
Pers Acc Inten Healthy Mean Median (Range)	N=1 36 36 (36-36)	N=1 37 37 (37-37)	N=3 42.56 43.6 (36.4-47.7)	N=3 38.67 39 (36.3-40.70)	N=3 40.5 39 (39-43.5)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects who had no health needs identified at the health check

No health needs identified at health check (Healthy)	Group 1		Group 2		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer Healthy Mean Median (Range)	N=18 78.33 80 (35-100)	N=18 73.89 90 (25-100)	N=31 76.77 95 (0-100)	N=31 80.97 95 (0-100)	N=31 78.87 95 (0-100)
RP Carer Healthy Mean Median (Range)	N=18 51.39 50 (0-100)	N=18 63.89 75 (0-100)	N=31 73.39 100 (0-100) +	N=31 80.65 100 (0-100) ++Pre	N=31 80.65 100 (0-100)
BP Carer Healthy Mean Median (Range)	N=18 52.22 51 (0-100)	N=18 62.44 67 (0-100)	N=32 67.91 69 (0-100)	N=32 70.19 77 (0-100) +Pre	N=32 74 84 (0-100)
GH Carer Healthy Mean Median (Range)	N=17 56.12 60 (8-97)	N=17 59.41 62 (15-92)	N=30 65.03 72 (0-97)	N=30 69.53 74.5 (10-97)	N=30 69.43 76.5 (10-100)
VT Carer Healthy Mean Median (Range)	N=18 49.44 55 (10-100)	N=18 50.56 50 (20-80)	N=29 60.86 65 (10-100)	N=29 55.34 60 (5-90)	N=29 57.93 60 (10-95)
SF Carer Healthy Mean Median (Range)	N=18 81.94 100 (0-100)	N=18 74.31 81.25 (25-100)	N=31 77.82 87.5 (12.5-100)	N=31 77.82 75 (25-100)	N=31 79.84 87.5 (0-100)
RE Carer Healthy Mean Median (Range)	N=16 81.25 100 (0-100)	N=16 75 100 (0-100)	N=27 81.48 100 (0-100)	N=27 81.48 100 (0-100)	N=27 83.95 100 (0-100)
MH Carer Healthy Mean Median (Range)	N=18 70.89 74 (32-96)	N=18 68.89 70 (36-92)	N=29 75.03 80 (36-96)	N=29 72.97 72 (40-100)	N=29 74.62 76 (36-100)
MH Carer Healthy *Mean* *Median* *(Range)*	*N=18* *70.89* *74* *(32-96)*	*N=18* *68.89* *70* *(36-92)*	*N=29* *75.03* *80* *(36-96)*	*N=29* *72.97* *72* *(40-100)*	*N=29* *74.62* *76* *(36-100)*

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 25.

Scores for subjects who had one or more health needs identified at the health check and their carers

Scores for subjects who had one or more health needs identified at the health check

One or more health needs identified at health check (Unhealthy)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS Unhealthy Mean Median (Range)	N=57 166.42 176 (31-274)	N=57 163.26 169 (54-287)	N=34 164.09 163 (45-278)	N=34 163.15 173.5 (38-304)	N=34 170.68 174.5 (36-296) *1
PIMRA Unhealthy Mean Median (Range)	N=58 11.29 11 (1-30)	N=58 10.09 9.5 (0-36) *	N=34 10.94 10 (2-29)	N=34 8.94 8.5 (0-24) **	N=34 10.18 10 (1-25)
ABC Tot Unhealthy Mean Median (Range)	N=58 25.55 16.5 (0-87)	N=58 24.84 11 (0-104)	N=33 20.42 20 (0-78)	N=33 21.52 16 (0-92)	N=33 18.76 12 (0-55)
ABC TN Unhealthy Mean Median (Range)	N=58 15.91 12 (0-46)	N=58 15.84 10 (0-49)	N=33 15.18 15 (0-42)	N=33 15.36 14 (0-52)	N=33 14.55 11 (0-41)
ABC T3s Unhealthy Mean Median (Range)	N=58 2.55 0 (0-18)	N=58 2.17 0 (0-20)	N=33 1 0 (0-9)	N=33 1.09 0 (0-7)	N=33 0.73 0 (0-7)
IPDL Unhealthy Mean Median (Range)	N=58 7.95 9 (0-24)	N=58 7.57 7.5 (0-24)	N=35 8.37 9 (0-24)	N=35 7.80 9 (0-24)	N=35 8.66 8 (0-24)
Stancliff Unhealthy Mean Median (Range)	N=36 52.33 52 (37-72)	N=36 48.78 49 (35-68) •	N=13 49.69 52 (36-57)	N=13 50.85 52 (44-62)	N=13 48.62 49 (35-58)
ICI Unhealthy Mean Median (Range)	N=58 6.64 7 (2-12)	N=58 6.24 6 (1-11)	N=35 6.54 7 (2-11)	N=35 7.0 7 (3-12) *	N=35 6.46 6 (3-14)
ICI freq Unhealthy Mean Median (Range)	N=58 20.19 19.5 (6-43)	N=58 18.29 18.5 (2-40)	N=35 19.2 19 (2-34)	N=35 22.14 23 (9-34) +Post	N=35 20.03 21 (7-35)
Diary A Unhealthy Mean Median (Range)	N=56 1.61 0 (0-13)	N=56 0.63 0 (0-4.5) **	N=34 1.01 0 (0-7.5)	N=34 1.19 0 (0-6.5)	N=34 1.04 0 (0-9)
Diary B Unhealthy Mean Median (Range)	N=56 12.77 11 (0-33)	N=56 8.79 5.5 (0-26.5) •	N=34 13.28 11.64 (0-41)	N=34 10.10 8.5 (0-37)	N=34 8.10 4.25 (0-48) •1 *2

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects who had one or more health needs identified at the health check

One or more health needs identified at health check (Unhealthy)	Group 1		Group 2		
	Pre	Post	Pre 1	Pre 2	Post
EOS Unhealthy Mean Median (Range)	N=9 34.22 22 (1-91)	N=9 55.0 36 (8-123)	N=5 28 33 (0-68)	N=5 16.8 13 (4-42)	N=5 25.6 17 (3-68)
PF Patient Unhealthy Mean Median (Range)	N=56 52.05 62.5 (0-100)	N=56 50.54 47.5 (0-100)	N=34 66.47 70 (0-100)	N=34 65 70 (0-100)	N=34 52.06 55 (0-100) •1 ••2
RP Patient Unhealthy Mean Median (Range)	N=56 70.54 100 (0-100)	N=56 76.34 100 (0-100)	N=33 84.85 100 (0-100)	N=33 78.79 100 (0-100)	N=33 68.94 100 (0-100) *1
BP Patient Unhealthy Mean Median (Range)	N=56 75.35 84 (12-100)	N=56 78.77 84 (12-100)	N=31 74.19 74 (0-100)	N=31 86.19 100 (41-100) *	N=31 77.37 84 (2.5-100)
GH Patient Unhealthy Mean Median (Range)	N=53 59.15 62 (0-100)	N=53 57.42 62 (5-100)	N=31 67.19 67 (25-100)	N=31 67.16 67 (15-100)	N=31 66.77 70 (25-97)
VT Patient Unhealthy Mean Median (Range)	N=53 56.32 55 (5-95)	N=53 57.92 60 (5-90)	N=30 64.67 65 (20-100)	N=30 65.83 70 (20-100)	N=30 63.83 67.5 (5-90)
SF Patient Unhealthy Mean Median (Range)	N=56 77.90 87.5 (0-100)	N=56 79.02 93.75 (0-100)	N=35 75 87.5 (12.5-100)	N=35 78.57 100 (12.5-100)	N=35 84.29 100 (0-100)
RE Patient Unhealthy Mean Median (Range)	N=55 77.58 100 (0-100)	N=55 84.24 100 (0-100)	N=33 87.88 100 (0-100) +	N=33 75.76 100 (0-100)	N=33 87.88 100 (0-100)
MH Patient Unhealthy Mean Median (Range)	N=53 67.85 72 (20-100)	N=53 75.70 76 (28-100) •	N=30 75.6 78 (40-100)	N=30 77.57 80 (36-100) +Pre	N=30 77.47 80 (8-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects who had one or more health needs identified at the health check

One or more health needs identified at health check (Unhealthy)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise Unhealthy Mean Median (Range)	N=18 6.06 6.5 (0.5-12)	N=18 5.58 5 (0-16)	N=15 4.9 4.5 (0-15)	N=15 5 4 (0-14)	N=15 5.1 5 (0-10.5)
Carer Index Unhealthy Mean Median (Range)	N=18 5.78 4.5 (0-13)	N=18 5.22 4.5 (0-12)	N=14 4 3 (0-13)	N=14 3.5 3 (0-11)	N=14 3.14 1.5 (0-10)
Emot Ex Freq Unhealthy Mean Median (Range)	N=10 10.9 10.35 (1.5-21.4)	N=10 18.66 18.8 (6-32)	N=0	N=0	N=0
Emot Ex Inten Unhealthy Mean Median (Range)	N=9 15.27 15.3 (7-22.5)	N=9 24.99 26.7 (13.7-36) **	N=0	N=0	N=0
Depers Freq Unhealthy Mean Median (Range)	N=10 4.13 3.4 (0.3-8.4)	N=10 3.5 5 (0-7)	N=0	N=0	N=0
Depers Inten Unhealthy Mean Median (Range)	N=9 5.18 3.7 (2.7-8.4)	N=9 5.03 5 (0-12.7)	N=0	N=0	N=0
Pers Acc Freq Unhealthy Mean Median (Range)	N=10 39.18 38.35 (33-45.5)	N=10 38.01 37.4 (31.7-46)	N=0	N=0	N=0
Pers Acc Inten Unhealthy Mean Median (Range)	N=8 37.49 37.5 (33-43)	N=8 39.36 38.4 (32-49)	N=0	N=0	N=0

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects who had one or more health needs identified at the health check

One or more health needs identified at health check (Unhealthy)	Group 1		Group 2		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer Unhealthy Mean Median (Range)	N=33 72.42 85 (5-100)	N=33 71.21 85 (0-100)	N=22 66.82 77.5 (0-100)	N=22 75.23 87.5 (30-100)	N=22 73.18 75 (25-100)
RP Carer Unhealthy Mean Median (Range)	N=34 71.47 100 (0-100)	N=34 64.71 100 (0-100)	N=22 54.55 50 (0-100)	N=22 55.68 62.5 (0-100)	N=22 75 100 (0-100)
BP Carer Unhealthy Mean Median (Range)	N=34 66.26 72 (12-100)	N=34 63.53 67 (21-100)	N=22 61.73 62 (0-100)	N=22 68.73 84 (0-100)	N=22 69.91 74 (12-100)
GH Carer Unhealthy Mean Median (Range)	N=34 64.88 71 (10-100)	N=34 60.97 69.5 (5-100)	N=20 48.15 47.5 (10-100) ++	N=20 59.5 62 (25-100) *	N=20 62.4 66 (25-100) **1
VT Carer Unhealthy Mean Median (Range)	N=33 60.76 70 (5-95)	N=33 52.73 55 (0-95) *	N=22 56.59 60 (10-90)	N=22 59.09 62.5 (25-90)	N=22 58.86 62.5 (15-85)
SF Carer Unhealthy Mean Median (Range)	N=34 80.15 100 (0-100)	N=34 79.04 100 (0-100)	N=22 72.16 75 (12.5-100)	N=22 69.32 75 (0-100)	N=22 82.95 87.5 (25-100) *2
RE Carer Unhealthy Mean Median (Range)	N=32 84.38 100 (0-100)	N=32 72.92 100 (0-100)	N=20 65 100 (0-100)	N=20 65 100 (0-100)	N=20 80 100 (0-100) *2
MH Carer Unhealthy Mean Median (Range)	N=33 78.79 84 (32-100)	N=33 75.39 80 (4-100)	N=21 70.48 72 (44-96) +	N=21 70.29 68 (36-92) +Pre	N=21 73.90 76 (48-100)
MH Carer Unhealthy *Mean* *Median* *(Range)*	*N=33* *78.79* *84* *(32-100)*	*N=33* *75.39* *80* *(4-100)*	*N=22* *68.18* *70* *(20-96) +*	*N=22* *68.91* *68* *(36-92) +Pre +Post*	*N=22* *74.55* *76* *(48-100)*

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 26.

Scores for subjects who had all identified health needs treated and their carers

Scores for subjects who had all identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS Treated Mean Median (Range)	N=22 163.95 173 (54-259)	N=22 166.82 173 (55-286)	N=17 143.06 151 (45-247)	N=17 142.18 144 (38-232)	N=17 151.18 154 (36-262)
PIMRA Treated Mean Median (Range)	N=23 10.26 8 (1-23)	N=23 7.78 7 (1-17) *	N=18 11.67 11 (2-20)	N=18 8.61 9 (0-16) **	N=18 9.94 10 (3-17) *1
ABC Tot Treated Mean Median (Range)	N=23 20.52 16 (1-77)	N=23 15.70 9 (0-54)	N=17 19.53 20 (0-44)	N=17 21 19 (0-61)	N=17 21.41 18 (0-48)
ABC TN Treated Mean Median (Range)	N=23 13.87 12 (1-35)	N=23 12 8 (0-37)	N=17 15.18 13 (0-34)	N=17 15.53 18 (0-38)	N=17 17.53 15 (0-41)
ABC T3s Treated Mean Median (Range)	N=23 1.35 0 (0-16)	N=23 0.57 (0-4)	N=17 0.82 0 (0-3)	N=17 1.47 0 (0-7)	N=17 0.59 0 (0-5)
IPDL Treated Mean Median (Range)	N=23 7.43 9 (0-24)	N=23 7.35 8 (0-24)	N=18 5.56 3 (0-13)	N=18 5.44 4.5 (0-15)	N=18 6.44 5.5 (0-15)
Stancliff Treated Mean Median (Range)	N=12 51.75 50 (40-72)	N=12 49.33 48.50 (40-65)	N=7 48.57 52 (36-57)	N=7 49.57 47 (44-62)	N=7 49.29 53 (35-58)
ICI Treated Mean Median (Range)	N=23 6.26 6 (2-10)	N=23 6.22 7 (1-11)	N=18 5.5 5 (2-10)	N=18 6.44 6.5 (3-12) *	N=18 5.89 6 (3-9)
ICI freq Treated Mean Median (Range)	N=23 17.87 18 (6-31)	N=23 17.43 19 (2-34)	N=18 16 13 (2-32)	N=18 20.28 20.5 (9-31) **	N=18 19.39 18.5 (7-35) *1
Diary A Treated Mean Median (Range)	N=23 1.26 0 (0-8)	N=23 0.78 0 (0-4.5)	N=18 0.89 0 (0-7)	N=18 1.17 0 (0-6.5)	N=18 0.89 0 (0-4.5)
Diary B Treated Mean Median (Range)	N=23 11 9.5 (0-33)	N=23 6.57 3 (0-26.5) *	N=18 10.83 5.75 (0-34.5)	N=18 9.17 9.25 (0-20)	N=18 4.22 2.5 (0-20) •1 *2

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

Epilepsy Outcome Scale and SF-36 scores for subjects who had all identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS Treated	N=3	N=3	N=3	N=3	N=3
Mean	50.33	86	22.67	17	29.33
Median	63	99	0	5	17
(Range)	(6-82)	(36-123)	(0-68)	(4-42)	(3-38)
PF Subject Treated	N=23	N=23	N=18	N=18	N=18
Mean	50.43	49.13	59.17	57.5	46.39
Median	70	45	65	70	47.5
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
RP Subject Treated	N=23	N=23	N=18	N=18	N=18
Mean	68.48	73.91	84.72	76.39	73.61
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
BP Subject Treated	N=23	N=23	N=17	N=17	N=17
Mean	69.07	73.91	79.88	87.82	83.53
Median	84	74	100	100	100
(Range)	(24-100)	(12-100)	(0-100)	(41-100) +Pre	(10-100)
GH Subject Treated	N=22	N=22	N=16	N=16	N=16
Mean	58.23	57.95	63.75	67	64
Median	64.5	64.5	67	69.5	64.5
(Range)	(5-92)	(5-97)	(25-100)	(15-92)	(25-97)
VT Subject Treated	N=22	N=22	N=16	N=16	N=16
Mean	58.18	62.5	66.56	66.56	64.69
Median	60	60	72.5	72.5	67.5
(Range)	(5-90)	(20-90)	(20-100)	(20-95)	(25-90)
SF Subject Treated	N=23	N=23	N=18	N=18	N=18
Mean	72.28	85.33	77.08	84.03	88.19
Median	75	100	100	100	100
(Range)	(0-100)	(37.5-100)	(12.5-100)	(12.5-100)	(25-100) **2
RE Subject Treated	N=22	N=22	N=18	N=18	N=18
Mean	75.76	90.91	94.44	77.78	85.19
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100) +	(0-100)	(0-100)
MH Subject Treated	N=22	N=22	N=16	N=16	N=16
Mean	70.18	80.18	76.75	75.25	77.25
Median	76	86	80	80	78
(Range)	(20-92)	(48-100) *	(40-100)	(36-100)	(40-100)

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects who had all identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise Treated Mean Median (Range)	N=10 5.5 5.5 (1-12)	N=10 6 5 (0-16)	N=8 4.06 3.25 (1-8.5)	N=8 4.75 4.25 (1-10.5)	N=8 4.69 3.75 (0-10.5)
Carer Index Treated Mean Median (Range)	N=10 4.5 4 (0-10)	N=10 4.1 2.5 (0-12)	N=8 3.38 2 (0-13)	N=8 3.63 3 (0-11)	N=8 3 1.5 (0-10)
Emot Ex Freq Treated Mean Median (Range)	N=2 7.35 7.35 (4.7-10)	N=2 22.15 22.15 (12.3-32)	N=0	N=0	N=0
Emot Ex Inten Treated Mean Median (Range)	N=2 10.35 10.35 (7-13.7)	N=2 21.55 21.55 (13.7-29.4)	N=0	N=0	N=0
Depers Freq Treated Mean Median (Range)	N=2 4.15 4.15 (0.3-8)	N=2 2.5 2.5 (0-5)	N=0	N=0	N=0
Depers Inten Treated Mean Median (Range)	N=2 5.35 5.35 (2.7-8)	N=2 2.5 2.5 (0-5)	N=0	N=0	N=0
Pers Acc Freq Treated Mean Median (Range)	N=2 38.85 38.85 (36-41.7)	N=2 40.05 40.05 (37.4-42.7)	N=0	N=0	N=0
Pers Acc Inten Treated Mean Median (Range)	N=2 37.35 37.35 (33.7-41)	N=2 41.2 41.2 (38.4-44)	N=0	N=0	N=0

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects who had all identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer Treated Mean Median (Range)	N=13 63.85 80 (5-100)	N=13 65.77 70 (15-100)	N=12 70 80 (0-100)	N=12 70.42 72.5 (30-100)	N=12 72.08 72.5 (30-100)
RP Carer Treated Mean Median (Range)	N=13 65.38 100 (0-100)	N=13 61.54 (0-100)	N=12 75 100 (0-100)	N=12 68.75 87.5 (25-100)	N=12 70.83 87.5 (0-100)
BP Carer Treated Mean Median (Range)	N=13 58.54 51 (22-100)	N=13 53.08 52 (22-100)	N=12 72.5 73 (22-100)	N=12 76.5 84 (22-100) +Post	N=12 78.42 79 (22-100) *1 +
GH Carer Treated Mean Median (Range)	N=13 62.69 70 (10-100)	N=13 56.08 60 (5-97)	N=10 48.4 54.5 (10-77)	N=10 63.9 69.5 (25-100) *	N=10 66.6 67.5 (25-100) *1
VT Carer Treated Mean Median (Range)	N=13 56.92 60 (5-95)	N=13 50.38 55 (5-80)	N=12 62.92 72.5 (10-90)	N=12 65 67.5 (35-90)	N=12 63.75 70 (15-85)
SF Carer Treated Mean Median (Range)	N=13 79.81 100 (12.5-100)	N=13 79.81 100 (25-100)	N=12 83.33 100 (25-100)	N=12 84.38 87.5 (25-100)	N=12 86.46 93.75 (50-100)
RE Carer Treated Mean Median (Range)	N=13 79.49 100 (0-100)	N=13 66.67 100 (0-100)	N=11 81.82 100 (0-100)	N=11 75.76 100 (0-100)	N=11 84.85 100 (0-100)
MH Carer Treated Mean Median (Range)	N=13 80.62 84 (36-96)	N=13 81.85 88 (44-100)	N=12 71.33 74 (44-96)	N=12 73.33 72 (44-92)	N=12 75.67 76 (52-100)
MH Carer Treated *Mean* *Median* *(Range)*	*N=13* *80.62* *84* *(36-96)*	*N=13* *81.85* *88* *(44-100)*	*N=12* *71.33* *74* *(44-96)*	*N=12* *73.33* *72* *(44-92)*	*N=12* *75.67* *76* *(52-100)*

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 27.

Scores for subjects who had identified health needs partly treated and their carers

Scores for subjects who had identified health needs partly treated

Health needs identified were partly treated (Partly)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS Partly Mean Median (Range)	N=13 159.15 157 (68-256)	N=13 151.69 141 (70-240)	N=6 179.83 171.5 (93-278)	N=6 191 190.5 (92-278)	N=6 183.17 (110-267)
PIMRA Partly Mean Median (Range)	N=13 12.31 13 (5-20)	N=13 13.31 12 (6-31)	N=6 8.17 10 (3-12)	N=6 7.5 8 (2-11) +Post	N=6 10.33 10.5 (1-19)
ABC Tot Partly Mean Median (Range)	N=13 30 26 (0-66)	N=13 35.69 37 (0-104)	N=6 25.67 23.5 (0-56)	N=6 21.17 10.5 (0-50)	N=6 11.5 13 (3-17)
ABC TN Partly Mean Median (Range)	N=13 18.15 20 (0-36)	N=13 20.62 21 (0-47)	N=6 16.33 18.5 (0-34)	N=6 13.67 9.5 (0-31)	N=6 10 11 (3-14)
ABC T3s Partly Mean Median (Range)	N=13 3.54 0 (0-14)	N=13 4.69 1 (0-20)	N=6 1.67 0 (0-8)	N=6 0.67 0 (0-3)	N=6 0 0 (0-0) +
IPDL Partly Mean Median (Range)	N=13 5.77 6 (0-12)	N=13 6.69 4 (0-22)	N=6 9.17 6.5 (2-24)	N=6 8.83 8 (2-20)	N=6 9.67 6.5 (5-23)
Stancliff Partly Mean Median (Range)	N=7 48.86 46 (37-59)	N=7 47.29 45 (35-56)	N=1 46 46 (46-46)	N=1 52 52 (52-52)	N=1 45 45 (45-45)
ICI Partly Mean Median (Range)	N=13 7.08 7 (2-12)	N=13 6.15 6 (4-11)	N=6 6 6.5 (4-7)	N=6 7.67 8 (5-10)	N=6 6.17 7 (4-7)
ICI freq Partly Mean Median (Range)	N=13 22.85 21 (7-43)	N=13 17.85 18 (5-40)	N=6 17.5 18.5 (10-21)	N=6 24.83 24.5 (21-32) * +Post	N=6 17.33 18 (11-24) *2
Diary A Partly Mean Median (Range)	N=12 0.63 0 (0-3)	N=12 0.42 0 (0-2.5)	N=6 2.5 1.25 (0-7.5)	N=6 1.67 1 (0-4.5)	N=6 2.92 1 (0-9)
Diary B Partly Mean Median (Range)	N=12 10.04 10.25 (2.5-25)	N=12 7.58 5.5 (0-26)	N=6 12.08 9.75 (4.5-22)	N=6 8.67 8.5 (2-19)	N=6 7.42 7.25 (2-12.5)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Epilepsy Outcome scale and SF-36 scores for subjects who had identified health needs partly treated

Health needs identified were partly treated (Partly)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS Partly Mean Median (Range)	N=3 38 22 (1-91)	N=3 42.33 21 (9-97)	N=1 33 33 (33-33)	N=1 13 13 (13-13)	N=7 7 7 (7-7)
PF Subject Partly Mean Median (Range)	N=12 39.17 30 (0-100)	N=12 38.75 32.5 (0-95)	N=5 78 80 (60-100)	N=5 75 75 (55-90)	N=5 66 65 (40-90) *1
RP Subject Partly Mean Median (Range)	N=12 66.67 75 (0-100)	N=12 77.08 100 (0-100)	N=5 90 100 (50-100)	N=5 85 100 (50-100)	N=5 60 50 (25-100)
BP Subject Partly Mean Median (Range)	N=12 82.08 92 (32-100)	N=12 74.5 79 (22-100)	N=5 64.2 54 (41-100)	N=5 82.8 84 (72-100)	N=5 72.6 74 (31-100)
GH Subject Partly Mean Median (Range)	N=12 62.42 63.5 (15-97)	N=12 68.42 67 (35-100)	N=6 77.67 82.5 (52-100)	N=6 78.67 77 (67-92)	N=6 75.83 78.5 (47-97)
VT Subject Partly Mean Median (Range)	N=12 40 40 (10-80)	N=12 56.25 55 (40-85) *	N=5 63 60 (45-90) +	N=5 67 60 (55-85) +Pre	N=5 69 75 (40-85)
SF Subject Partly Mean Median (Range)	N=12 79.17 93.75 (12.5-100)	N=12 85.42 93.75 (37.5-100)	N=6 64.58 62.5 (50-87.5)	N=6 83.33 100 (50-100)	N=6 81.25 93.75 (37.5-100)
RE Subject Partly Mean Median (Range)	N=12 88.89 100 (33.33-100)	N=12 91.67 100 (0-100)	N=5 80 100 (0-100)	N=5 100 100 (100-100)	N=5 93.33 100 (66.67-100)
MH Subject Partly Mean Median (Range)	N=12 64.33 66 (40-88)	N=12 73.33 72 (52-92)	N=5 81.6 80 (68-96) +	N=5 87.5 88 (76-96) ++Pre +Post	N=5 84.8 84 (72-100)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

Stress and burnout scores for the carers of subjects who had identified health needs partly treated

Health needs identified were partly treated (Partly)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise Partly Mean Median (Range)	N=5 6.6 6 (0.5-12)	N=5 5.3 5 (0.5-10)	N=3 9 8 (4-15)	N=3 8.83 10 (2.5-14)	N=3 6.67 7 (5-8)
Carer Index Partly Mean Median (Range)	N=5 6 4 (1-13)	N=5 5.4 5 (2-11)	N=3 6.67 4 (4-12)	N=3 4.67 4 (2-8)	N=3 5 5 (1-9)
Emot Ex Freq Partly Mean Median (Range)	N=2 5.75 5.75 (1.5-10)	N=2 21.75 21.75 (11.5-32)	N=0	N=0	N=0
Emot Ex Inten Partly Mean Median (Range)	N=1 13.7 13.7 (13.7-13.7)	N=1 29.4 29.4 (29.4-29.4)	N=0	N=0	N=0
Depers Freq Partly Mean Median (Range)	N=2 4.75 4.75 (1.5-8)	N=2 2.5 2.5 (0-5)	N=0	N=0	N=0
Depers Inten Partly Mean Median (Range)	N=1 8 8 (8-8)	N=1 5 5 (5-5)	N=0	N=0	N=0
Pers Acc Freq Partly Mean Median (Range)	N=2 40.25 40.25 (36-44.5)	N=2 38.95 38.95 (37.4-40.5)	N=0	N=0	N=0
Pers Acc Inten Partly Mean Median (Range)	N=1 33.7 33.7 (33.7-33.7)	N=1 38.4 38.4 (38.4-38.4)	N=0	N=0	N=0

* Significant within group change at p<0.05
** Significant within group change at p<0.01
• Significant within group change at p<0.005
•• Significant within group change at p<0.001

\+ Significant between group difference at p<0.05
++ Significant between group difference at p<0.01
† Significant between group difference at p<0.005
†† Significant between group difference at p<0.001

SF-36 scores for the carers of subjects who had identified health needs partly treated

Health needs identified were partly treated (Partly)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer Partly	N=9	N=9	N=4	N=4	N=4
Mean	79.44	78.89	56.25	75	70
Median	95	95	62.5	80	75
(Range)	(10-100)	(0-100)	(30-70)	(40-100)	(30-100)
RP Carer Partly	N=9	N=9	N=4	N=4	N=4
Mean	78.33	72.22	12.5	31.25	50
Median	100	100	0	12.5	50
(Range)	(0-100)	(0-100)	(0-50) +	(0-100)	(0-100)
BP Carer Partly	N=9	N=9	N=4	N=4	N=4
Mean	74.22	74.56	41.5	65.75	42
Median	74	84	41	70.5	42
(Range)	(12-100)	(21-100)	(0-84)	(22-100)	(12-72)
GH Carer Partly	N=9	N=9	N=4	N=4	N=4
Mean	70.56	72.44	45	55	63.5
Median	72	87	30	55	63.5
(Range)	(47-90)	(12-100)	(20-100)	(25-85)	(30-97)
VT Carer Partly	N=8	N=8	N=4	N=4	N=4
Mean	57.5	53.13	43.75	51.25	50
Median	70	60	42.5	50	50
(Range)	(5-85)	(0-95)	(25-65)	(35-70)	(25-75)
SF Carer Partly	N=9	N=9	N=4	N=4	N=4
Mean	73.61	77.78	46.88	59.38	68.75
Median	100	100	50	68.75	81.25
(Range)	(0-100)	(0-100)	(12.5-75)	(12.5-87.5)	(25-87.5)
RE Carer Partly	N=9	N=9	N=4	N=4	N=4
Mean	88.89	77.78	25	25	41.67
Median	100	100	16.67	0	33.33
(Range)	(0-100)	(0-100)	(0-66.67) ++	(0-100) +Pre	(0-100)
MH Carer Partly	N=8	N=8	N=4	N=4	N=4
Mean	74.5	67.5	67	57	71
Median	78	72	66	60	70
(Range)	(40-100)	(12-100)	(56-80)	(36-72)	(52-92)
MH Carer Partly	*N=8*	*N=8*	*N=4*	*N=4*	*N=4*
Mean	*74.5*	*67.5*	*67*	*57*	*71*
Median	*78*	*72*	*66*	*60*	*70*
(Range)	*(40-100)*	*(12-100)*	*(56-80)*	*(36-72)*	*(52-92)*

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
●	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
●●	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.

Appendix 28.

Scores for subjects who had none of identified health needs treated and their carers

Scores for subjects who had none of identified health needs treated

Health needs identified remained untreated (Untreated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
ABS Untreated Mean Median (Range)	N=22 173.18 187 (31-274)	N=22 166.55 170 (54-287)	N=11 188 185 (58-278)	N=11 180.36 189 (68-304)	N=11 194 212 (65-296)
PIMRA Untreated Mean Median (Range)	N=22 11.77 11 (2-30)	N=22 10.59 10 (0-36)	N=10 11.3 8.5 (4-29)	N=10 10.4 9 (1-24)	N=10 10.5 9.5 (1-25)
ABC Tot Untreated Mean Median (Range)	N=22 28.18 16.5 (2-87)	N=22 28 10.5 (2-79)	N=10 18.8 12.5 (3-78)	N=10 22.6 10.5 (1-92)	N=10 18.6 8.5 (0-55)
ABC TN Untreated Mean Median (Range)	N=22 16.73 12 (0-46)	N=22 17.05 9.5 (2-49)	N=10 14.5 12.5 (3-42)	N=10 16.1 9.5 (1-52)	N=10 12.2 7 (0-33)
ABC T3s Untreated Mean Median (Range)	N=22 3.23 0 (0-18)	N=22 2.36 0.5 (0-14)	N=10 0.9 0 (0-9)	N=10 0.7 0 (0-3)	N=10 1.4 0.5 (0-7)
IPDL Untreated Mean Median (Range)	N=22 9.77 11 (0-22)	N=22 8.32 8 (0-23)	N=11 12.55 11 (0-24)	N=11 11.09 11 (0-24)	N=11 11.73 10 (3-24)
Stancliff Untreated Mean Median (Range)	N=17 54.18 56 (38-68)	N=17 49 50 (40-68) **	N=5 52 52 (48-57)	N=5 52.4 53 (46-56)	N=5 48.4 47 (41-55)
ICI Untreated Mean Median (Range)	N=22 6.77 7 (3-10)	N=22 6.32 7 (2-11)	N=11 8.55 8 (5-11) +	N=11 7.55 8 (5-9) *	N=11 7.55 7 (4-14)
ICI freq Untreated Mean Median (Range)	N=22 21.05 21 (10-32)	N=22 19.45 19 (2-32)	N=11 25.36 26 (11-34)	N=11 23.73 24 (9-34)	N=11 22.55 24 (8-35)
Diary A Untreated Mean Median (Range)	N=21 2.55 1 (0-13)	N=21 0.60 0 (0-4) *	N=10 0.35 0 (0-1.5)	N=10 0.95 0 (0-4.5)	N=10 0.2 0 (0-1)
Diary B Untreated Mean Median (Range)	N=21 16.26 14 (0-32)	N=21 11.93 12.5 (0-26) *	N=10 18.4 14 (0-41)	N=10 12.65 5 (2-37)	N=10 15.5 6.5 (0-48)

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
●	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
●●	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for subjects who had none of identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
EOS Untreated	N=3	N=3	N=1	N=1	N=1
Mean	14.33	36.67	39	20	33
Median	3	23	39	20	33
(Range)	(1-39)	(8-79)	(39-39)	(20-20)	(33-33)
PF Subject Untreated	N=21	N=21	N=11	N=11	N=11
Mean	61.19	58.81	73.18	72.73	55
Median	70	50	85	90	55
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(5-100) *1 *2
RP Subject Untreated	N=21	N=21	N=10	N=10	N=10
Mean	75	78.57	82.5	80	65
Median	100	100	100	100	87.5
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
BP Subject Untreated	N=21	N=21	N=9	N=9	N=9
Mean	78.38	86.52	69	85	68.39
Median	84	100	62	100	84
(Range)	(12-100)	(41-100)	(31-100)	(41-100)	(2.5-100)
GH Subject Untreated	N=19	N=19	N=9	N=9	N=9
Mean	58.16	49.84	66.33	59.78	65.67
Median	57	52	72	57	62
(Range)	(0-100)	(5-92)	(30-92)	(20-100)	(35-95)
VT Subject Untreated	N=19	N=19	N=9	N=9	N=9
Mean	64.47	53.68	62.22	63.89	59.44
Median	70	60	60	60	65
(Range)	(20-95)	(5-85)	(65-100)	(25-100)	(5-90)
SF Subject Untreated	N=21	N=21	N=11	N=11	N=11
Mean	83.33	68.45	77.27	67.05	79.55
Median	100	87.5	87.5	50	100
(Range)	(37.5-100)	(0-100)	(25-100)	(37.5-100)	(0-100)
RE Subject Untreated	N=21	N=21	N=10	N=10	N=10
Mean	73.02	73.02	80	60	90
Median	100	100	100	100	100
(Range)	(0-100)	(0-100)	(0-100)	(0-100)	(0-100)
MH Subject Untreated	N=19	N=19	N=9	N=9	N=9
Mean	67.37	72	70.22	76.33	73.78
Median	72	76	68	75	80
(Range)	(24-100)	(28-92)	(48-92)	(64-96)	(8-96)

* Significant within group change at $p<0.05$
** Significant within group change at $p<0.01$
• Significant within group change at $p<0.005$
•• Significant within group change at $p<0.001$

\+ Significant between group difference at $p<0.05$
++ Significant between group difference at $p<0.01$
† Significant between group difference at $p<0.005$
†† Significant between group difference at $p<0.001$

Stress and burnout scores for the carers of subjects who had none of identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
Malaise Untreated Mean Median (Range)	N=3 7 7 (5-9)	N=3 4.67 6 (1-7)	N=4 3.5 4.5 (0-5) +	N=4 2.63 2.5 (0-5.5)	N=4 4.75 5.5 (0-8)
Carer Index Untreated Mean Median (Range)	N=3 9.67 9 (8-12)	N=3 8.67 9 (7-10)	N=3 3 2 (0-7)	N=3 2 0 (0-6) +Pre +Post	N=3 1.67 1 (0-4)
Emot Ex Freq Untreated Mean Median (Range)	N=6 13.8 13.85 (7-21.4)	N=6 16.47 18.8 (6-22)	N=0	N=0	N=0
Emot Ex Inten Untreated Mean Median (Range)	N=6 17.17 18.5 (8.5-22.5)	N=6 25.4 23.2 (18.7-36) *	N=0	N=0	N=0
Depers Freq Untreated Mean Median (Range)	N=6 3.92 3.4 (1-8.4)	N=6 4.17 5.5 (0-7)	N=0	N=0	N=0
Depers Inten Untreated Mean Median (Range)	N=6 4.65 3.6 (3-8.4)	N=6 5.88 5.15 (1.3-12.7)	N=0	N=0	N=0
Pers Acc Freq Untreated Mean Median (Range)	N=6 38.93 38.35 (33-45.5)	N=6 37.02 34.5 (31.7-46)	N=0	N=0	N=0
Pers Acc Inten Untreated Mean Median (Range)	N=5 38.3 38 (33-43)	N=5 38.82 37 (32-49)	N=0	N=0	N=0

*	Significant within group change at p<0.05	+	Significant between group difference at p<0.05
**	Significant within group change at p<0.01	++	Significant between group difference at p<0.01
•	Significant within group change at p<0.005	†	Significant between group difference at p<0.005
••	Significant within group change at p<0.001	††	Significant between group difference at p<0.001

SF-36 scores for the carers of subjects who had none of identified health needs treated

All health needs identified were treated (Treated)	Group A		Group B		
	Pre	Post	Pre 1	Pre 2	Post
PF Carer Untreated Mean Median (Range)	N=11 76.82 85 (30-100)	N=11 71.36 85 (30-95)	N=6 67.5 77.5 (20-95)	N=6 85 95 (35-100)	N=6 77.5 87.5 (25-100)
RP Carer Untreated Mean Median (Range)	N=12 72.92 100 (0-100)	N=12 62.5 87.5 (0-100)	N=6 41.67 37.5 (0-100)	N=6 45.83 37.5 (0-100)	N=6 100 100 (100-100) *1 +
BP Carer Untreated Mean Median (Range)	N=12 68.67 67 (25-100)	N=12 66.58 62 (32-100)	N=6 53.67 56.5 (31-75)	N=6 55.17 57.5 (0-100)	N=6 71.5 73 (31-100)
GH Carer Untreated Mean Median (Range)	N=12 63 69.5 (35-77)	N=12 57.67 63.5 (20-87)	N=6 49.83 47.5 (15-72)	N=6 55.17 48.5 (30-87)	N=6 54.67 53.5 (27-87)
VT Carer Untreated Mean Median (Range)	N=12 67.08 72.5 (30-90)	N=12 55 55 (0-80) *	N=6 52.5 60 (20-70)	N=6 52.5 52.5 (25-85)	N=6 55 50 (30-85)
SF Carer Untreated Mean Median (Range)	N=12 85.12 93.75 (25-100)	N=12 79.17 93.75 (25-100)	N=6 66.67 68.75 (25-100)	N=6 45.83 50 (0-75) ++Pre +Post	N=6 85.42 100 (37.5-100) *2
RE Carer Untreated Mean Median (Range)	N=10 86.67 100 (0-100)	N=10 76.67 100 (0-100)	N=5 60 66.67 (0-100)	N=5 73.33 100 (0-100)	N=5 100 100 (100-100)
MH Carer Untreated Mean Median (Range)	N=12 79.67 86 (32-100)	N=12 73.67 80 (4-92)	N=5 71.20 72 (64-84)	N=5 73.6 76 (52-88)	N=5 72 76 (48-92)
MH Carer Untreated *Mean* *Median* *(Range)*	*N=12* *79.67* *86* *(32-100)*	*N=12* *73.67* *80* *(4-92)*	*N=6* *62.67* *68* *(20-84)*	*N=6* *68* *72* *(40-88)*	*N=6* *74.67* *76* *(48-92)*

* Significant within group change at p<0.05	+ Significant between group difference at p<0.05
** Significant within group change at p<0.01	++ Significant between group difference at p<0.01
• Significant within group change at p<0.005	† Significant between group difference at p<0.005
•• Significant within group change at p<0.001	†† Significant between group difference at p<0.001

NB. The figures in italics indicate the scores before the outlier was removed from the data.