

**FRIENDS OF MIDLOTHIAN'S CHILDREN**

**A FEASIBILITY STUDY**

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## **FRIENDS OF MIDLOTHIAN'S CHILDREN**

### **Essential items and respite care for children in need in Midlothian**

#### **Recognised as a Scottish Charity: SC030479**

The Friends of Midlothian's Children was recognised as a Scottish Charity by the Inland Revenue on August 30th, 2000. The charity was set up as a membership organisation. The Friends consists of people from all walks of life who pay an annual membership fee (£10) to belong to the organisation and who want to help children in need in Midlothian. Many businesses are Friends who pay a corporate membership fee (£50) or offer help in kind, or both.

The charity raises funds for essential items and respite breaks for children in need in Midlothian who are recommended through the Midlothian Social Work Centres and other Child Care Professionals. We work, for example, with Midlothian Sure Start Nurseries, Midlothian Young Carers (Children 1st) and Saltersgate School for special needs children.

At present we provide 32 weeks of caravan holidays for children and families. Our caravan, which we bought in 2002, is situated at the Berwick Holiday Centre at Berwick-Upon-Tweed. This year we are also leasing a caravan with disabled facilities for six weeks for special needs children and also providing some outreach respite care for children from Saltersgate School. These children will be using a purpose built respite home in Prestonpans, East Lothian run by the Aberlour Trust. There is unfortunately no such facility in Midlothian. These are pilot projects and we hope to raise enough funds in 2004 to buy a caravan with disabled facilities and to provide more outreach respite care in 2005. We also provide days out for the children and supply essential items, which range from shoes, clothes and schoolbags to beds and duvets.

We were fortunate enough in 2003 to be awarded a Small Regeneration Grant by Midlothian Council for the purpose of helping us to conduct a feasibility study into the need for respite care in Midlothian. Mr Charles Pelling of Stuart Crawford Associates, an Edinburgh based media and public relations consultancy, was given the task of preparing the feasibility study and this document summarises his findings.

Our charity has a management committee of eight. We feel that it is

important to point out that the committee all carry out their work on a voluntary basis. We work for many hours and we charge the absolute minimum for postage, cartridges etc. We are fortunate to have good contacts in the business community who help us with photocopying and mailings and stationery. The charity runs at the lowest possible cost so that the children can benefit from the money that is raised.

Dr Jacqueline McDonnell  
Chairman

*Patron: Miss Henny Dundas-Bekker of Arniston House. Chairman: Dr Jacqueline McDonnell. Vice Chairman: Dr Nancy McLean. Treasurer: Mrs Dawn Lawson. Secretary: Mrs Kerry Cringan. Caravan Co-ordinator: Mrs Isabella Duffy. Education Officer: Mrs Maureen Price. Membership Secretary: Mrs Gaynor Marshall. Committee member: Mr Mark Lawson*

## FRIENDS OF MIDLOTHIAN'S CHILDREN FEASIBILITY STUDY

### Aim

To assess the different needs for respite care for children and families in Midlothian with a view to applying for further grants for larger projects.

### Target groups

There are three distinct target groups:

- Children and families who need respite care
- Children and young people with special needs. Such as physical disabilities, mental health problems, etc
- Young carers

By assessing the different needs of the above groups this report will:

- Highlight the statistics on the numbers of children in need of respite care
- Identify the gaps in the provision of respite care, thus identifying where the 'Friends of Midlothian's Children' can fit in.

For the purposes of this study respite care is defined as:

***Respite care, in the form of a short break away from the normal environment, whether a few hours , a weekend or a holiday, serves as a relief in routine for both those who give and those who receive care. It is provided for families, children and young carers who, for whatever reason, face social exclusion and who would benefit from the help provided by such a service. It is first and foremost a planned strategy that strengthens families and helps them to continue to support each other at home.***

An additional definition issued by the Scottish office in March 1996 defines respite care as:

*Any service of limited duration which benefits a dependent person. The distinctive feature of respite care is that the break should be a positive experience for the cared for person and the carer in order to enhance the quality of their lives and to support their relationship. Respite care can be provided within or outwith an individual's home and may extend from a few hours to a few weeks.*

## **THE SCOTTISH EXECUTIVE PERSPECTIVE**

1. It may not be immediately apparent why an overview of the Executive's Social Justice strategy is relevant to the short-term aspirations of the Friends of Midlothian's Children. However the view of the Executive regarding their delivery of social justice is critical, since it sets the agenda for tackling poverty and disadvantage on a national basis. The strategy was developed as a response to clear evidence that previous interventions by government aimed at tackling deprivation and discrimination had not worked or been sustainable. The new strategy recognises that the reasons for social inclusion are complex and inter-related, and that issues such as housing, health, education and employment opportunities, fear of crime and poor environment are not issues that can be tackled in isolation. It is within this joined-up, cross cutting approach that additional resources which are available in the Scottish Budget 2003-06 are going to be used to sharpen the attack on poverty and disadvantage. It is within this broad context that all funding applications, that the Friends of Midlothian's Children may consider in the future, should be tailored.

2. In November 1999 the Executive published 'Social Justice..... a Scotland where everybody matters' (1), which set out targets and milestones for tackling poverty and injustice. This document lays out the underlying philosophy of the Executive's commitment to delivering a better life for the most disadvantaged people and communities in Scotland. The mission statement is as follows:

*'Social Justice is an investment in the people of Scotland and is the foundation of our prosperity. We are delivering social justice by improving public services for all, by tackling the social, educational and economic barriers that create inequality and by working to end poverty. We are investing to make every community a safe, attractive place to live, where everybody has the opportunity to make the most of their potential.'*

3. The goals which fall out of the mission statement are:

- The elimination of child poverty in a generation
- Enabling all our young people to contribute and develop life-skills
- Full employment by providing opportunities for all those who can work

- Securing dignity in old age
- Building strong, inclusive communities.

4. The third report, published in November 2002, presents an upbeat but not complacent overview of the progress to date. Perhaps one of the most significant aspects of the strategy is the formal commitment to Community Planning as the most practical and effective way to deliver better and more responsive services for the communities and promoting their well-being. The process will provide:

- A strategic vision for the whole area, covering the social, economic and environmental needs of the area and its communities. This means at a local level as well as authority wide
- Community engagement
- Partnership with the private and voluntary sectors as well as the public sector
- Community leadership

5. The Executive aims to learn the lessons from the local authorities ongoing experience of the value and challenges of Community Planning and is to introduce legislation that will make the process statutory. This is an important development since it will formalise the recognition of the voluntary sector as a key social partner and stakeholder. Niche providers, such as the Friends of Midlothian's Children, will gain the right, enshrined in law, to provide input to Community Planning.

6. The report measures progress by monitoring 29 key milestones, of which 6 are directly related to child welfare. The report shows that children are now getting a better start in life and highlights several important trends set against a baseline year of 1997:

- 14% of dependent children are living in workless households in 2002 compared with 19% in the baseline year
- In absolute terms (measured against 1996-7 low income threshold updated to remove inflation) the proportion of children in low income households is down from 34% to 21%
- The proportion of children attending a pre-school facility has increased for 3 year olds from 64% in 1999 to 82% in 2002 but is fairly static for 4 year olds where participation is almost 100%. No figures are provided for the proportion of

families with children between 0 and 3 years who attend similar facilities, such as Midlothian Sure Start.

### Conclusion

7. While the document is important for the reasons given above it has to be interpreted within the context of the Scottish Executive. Thus it will highlight areas of success and ignore or minimize the impact of those areas where success has proved more illusive. To do otherwise would constitute a form of political suicide. The issue of respite care for children and families is simply not addressed (although it is for the elderly); indeed the Social Inclusion Division of the Scottish Executive, who are the lead department within the Executive for the document, claim that any research on the subject would be relatively ground breaking and that little formal scientific research has been carried out on the scope and extent of the problem. They do however, accept that the problem is large and that services providing respite care should be improved. This is a key argument in any future funding application by the Friends of Midlothian's Children.

8. Clearly some of the goals which fall out of the mission statement are unachievable. The aspiration to eradicate child poverty within a generation is one such. A recently published report by Barnardo's Scotland (2) estimates that 1 in 3 children in Scotland live below the poverty line and that these children are more likely to grow up addicted to alcohol and drugs, become the perpetrators and victims of crime and suffer unemployment and homelessness in the future (3). Given the recognition, within 'Social Justice', that such issues cannot be viewed in isolation, but are complex and interwoven, it suggests that the overall picture is not as upbeat as the report suggests. To quote Tam Baillie, the Director of Policy for Barnardo's Scotland:

*'Poverty is the single biggest threat to a child's future. It is essential that poverty is attacked now if we are to affect future outcomes for children.'*

9. The Scottish Executive 2003 report is due to be published in December 2003. It is likely that the report will only provide the technical annex containing a statistical update on the 29 key milestones. At present it is not planned to publish an annual report, which may suggest little progress has been made in the last 12 months.

## **MDLOTHIAN PROFILE**

### Profile

10. Situated to the south east of Edinburgh, Midlothian covers an area of some 355 square kilometres. Located right in the middle of the Lothians, it stretches from the Pentland Hills to the Moorfoots and Lammermuirs. The development of Midlothian is inextricably linked to its neighbours, Edinburgh, East and West Lothian. The Lothians area has one of the fastest growing economies in the UK, and the current Structure Plan, due to end in 2005, is based upon continued growth in the Lothian economy and its population. Despite being the smallest of the four Lothian council areas, with 10% of the region's population and 20% of its land area, it is identified as accommodating 40% of development in the current Structure Plan, and is therefore at the start of a period of sustained growth. The current consultative draft of the new Structure Plan, to cover the period to 2015, states that:

*“The wealth created in the capital city and surrounding towns will be spread throughout the neighbouring councils over the next 15 years”*

11. The settlement strategy proposed in the draft of the new Plan focuses development in seven core development areas, one of which is North Midlothian, covering the communities of Dalkeith, Mayfield, Newtongrange and Gorebridge, the A701 corridor, and the Shawfair area in the north east corner of the district. The draft plan highlights the planned improvements for accessibility, including the reopening of the Waverley and Penicuik rail lines, the grade separation of the Sheriffhall junction and the A68 Dalkeith bypass.

12. The population of Midlothian is 81,000 and this is distributed amongst a number of small and medium towns. The population has risen gradually in recent years, and is projected to grow further over the next fifteen years due to people moving into the area for the reasons described above. In addition, the population structure will consist of a greater number of people in older age groups – the population of people aged 65+ is set to rise by 33% compared to 19% nationally.

## Economy

13. Midlothian's Gross Domestic Product (GDP), which is essentially a measure of its economic output, is estimated to be £668 million. Presently, Midlothian's GDP is ranked 27<sup>th</sup> lowest out of 32 local authorities in Scotland. GDP per person in Midlothian is £8,902.50 per annum. The Scottish GDP per person is £13,934.80 per annum. Therefore Midlothian GDP per person is almost a third less than the Scottish average.

14. Total gross household income for chief household earners in Midlothian for the period 1999/2000 breaks down as follows:

0 to £10,000	-	32%
£10,000 to £15,000	-	22%
£15,000 to £20,000	-	17%
£20,000+	-	30%

15. Overall 71% of all households in Midlothian have a chief household earner weekly income that is £404.31 or less, for males and £266.42 or less, for females. This is compared to a Scottish average wage of £447.70 or less, for males and £273.41 or less, for females.

16. The unemployment level in Midlothian is 2.8%. This compares to a Scottish average of 4.1% and a UK average of 3.1%. Although this suggests that Midlothian does not have a particularly high overall unemployment rate, it conceals long-term problems in specific areas that continue to demonstrate higher than average unemployment among males. These include Mayfield/Easthouses (6.2%), Gorebridge (5.3%), Woodburn (4.9%), Newtongrange (4.4%) and Dalkeith Newbattle (4.2%).

17. The conclusion that may be drawn is that while the overall unemployment rate in Midlothian compares favourably with the Scottish and UK averages, it conceals significant levels of poverty within the employed, especially amongst females whose weekly earnings are noticeably lower than both Scottish and Lothian levels. This should also be considered within the context of the official poverty line figure, defined as a household weekly income of £242.00.

## Lifelong Learning

18. The percentage of Midlothian school leavers for 1999-2000 going on to higher education was the second lowest in Scotland at 24% compared

with the national average of 32%. Moreover, in 1999-2000, Midlothian had the highest number of school leavers directly entering employment at 44% compared to the national average of 26%, which reinforces the statistics above concerning GDP and weekly income levels.

### Health and Wellbeing

19. Teenage pregnancies in Midlothian for 2001 were recorded at 184, or at a rate of 51.8 per 1,000 females in the age group. The trend since 1998 is upwards and compares with 127 teenage pregnancies for East Lothian, or a rate of 35.9 for the age group. Between 1998 and 2001 the percentage of births that were low weight increased from 4.6% to 5.6%. This increase is comparable to the rest of Lothian. Low Birthweight has been linked to poor eating habits and this may be one of the factors influencing the percentage of low birthweight babies in Midlothian.

### Socio-demographics (4)

20. Figures provided by the Scottish Executive statistics department reveal that the Lothians as a whole have the highest percentage of households with children in Scotland. 34% of all households in the Lothians have children, compared to 27% for the whole of Scotland.

21. The latest population estimates from the General Registry Office indicates that, at 2000, 24.4% of Midlothian's population was aged under 18 (largely in line with the national figure of 22%):

Age	0-4	5-9	10-14	15	16-17	Total
Population	4818	5223	5283	999	2003	18326

A breakdown of 0-14 year olds, by ward, is at Annex A.

22. On 29<sup>th</sup> April 2001 (Census Day) there were 2,377 single parents in Midlothian. This represented one in four (23%) of all households with children (10,459). The ward with the highest number of single parents was Easthouses/Mayfield North, where there were 206 single parents. This represents 9% of all single parents in Midlothian. A breakdown of single parents by ward is at Annex B.

23. Midlothian as an area saw 4,900 people claim Income Support during August 2002. Income Support can be paid to a person, aged 16 or over, is not working 16 hours or more a week and has less money coming in than the law says they need to live on. Data for 2002 was only available down

to local authority level but, set against population levels, would appear to be consistent with data for the previous four years. The ward with the highest number of Income Support claimants has historically been Easthouses/Mayfield North with about 515 persons claiming Income Support annually. Within Midlothian over 1,215 (26%) Income Support claimants are lone parents. Again the single largest group came from Easthouses/Mayfield North.

24. The latest data regarding the number of people claiming Family Credit is for the period March 1999 to August 1999. Family Credit is a weekly tax-free Social Security benefit for families of working people who are responsible for bringing up at least one child under the age of 16. Midlothian as an area saw 1,455 people claiming family credit during the period. The ward with the highest number of claimants was Easthouses/Mayfield North where 190 people claimed benefit. The wards of Woodburn (140), Penicuik North East (140), and Gorebridge (170) all had high numbers of family credit claimants. The majority of family credit claimants were single. Some 905 (65%) who claimed family credit were single.

25. During 2001/2002 14.7% (1983 children) of all Midlothian children received free school meals. This figure is lower than the Scottish figure (18.8%) and the second lowest within the Lothians. The majority of free meals come from the primary school sector suggesting that free meal usage changes due to factors such as stigma and incomes of parents as they advance through their various career paths or as their childcare needs diminish.

26. Another useful measurement is the Scottish Index of Multiple Deprivation 2003 (SIMD), compiled by the Social Disadvantage Research Centre for the Scottish Executive. SIMD Attempts to quantify poverty in Scotland by local authority ward, by measuring different dimensions of deprivation using the best indicators available. Low income is the central component in the definition of multiple deprivation for the SIMD, but other indicators include educational deprivation and health deprivation. The index does not include a separate domain that measures the lack of socially perceived necessities (e.g., adequate diet, consumer durables, ability to afford social activities, etc), as there are no readily available small area data in this field. However, low income is an important indicator of these aspects of material deprivation. These scores are then combined and weighted to generate an index of multiple deprivation. SIMD scores have been calculated for each of the 1222 wards in Scotland and then placed in a league table. The league table for

Midlothian is replicated at Annex C. Unsurprisingly, the three wards with the worst scores are Easthouses/Mayfield North (270th worst ward in Scotland), Dalkeith Woodburn (354) and Gorebridge South (450). Wards with the least deprivation are Penicuik North, Penicuik South West and Penicuik South East.

### Conclusion

27. Midlothian is a mixture of urban centres, former mining villages and rural areas. The economy has changed considerably in the last 20 years, with the rapid decline of its traditional industries, especially mining and paper manufacturing. In many ways Midlothian has coped well with this rapid change. Unemployment is slightly below the Scottish average. The area as a whole has a strong base in sectors such as retail, where future growth is anticipated. New industries with good growth potential are emerging, including the sectors of biotechnology and animal welfare. Projections anticipate a growth in both the economy and population of Midlothian.

28. However there are many worrying features of the local economy. Edinburgh dominates the local labour market with as many as half the workforce commuting daily into the capital. This has led to problems of congestion and pollution and limited opportunities for those without cars or access to public transport. It has also led to concerns about the long-term viability of many local shops and service in the towns and villages of Midlothian.

29. The workforce in Midlothian has fewer educational qualifications than the Scottish average, with a higher proportion of school leavers going directly into employment. The employed workforce, therefore, tends to be concentrated in lower order occupations and this is reflected in the fact that pay for an average full time worker is considerably lower than the Scottish average. Male part-time employment is very high and Midlothian has the highest incidence in Scotland of low earning, part-time employed women with earnings below the poverty line. Midlothian is generally a low waged economy. It is possible to infer from this that there are many families who would benefit from subsidised or wholly free short breaks away from their normal environment. To get a statistically valid figure would require formal market research, which is beyond the scope of this report.

30. The local economy, and local communities, continue to face major challenges in ensuring a sustainable future. These challenges are

particularly visible in areas centred around the former mining areas, where there are still pockets of high unemployment and poverty. These tend to be areas where educational achievement is lowest, part-time employment is high, car ownership is low, the number of lone parents is high and levels of home ownership low. Shops, services and the local environment are also often poor, providing those who are most limited in their mobility with the fewest options and hindering the attraction of new business and inward investment. Premises for housing community activities and community services are generally lacking, hindering both the sustainability of what is there and limiting the development of new activities.

31. While much has been done by the local council, other agencies and community organisations to tackle these issues, poverty and social exclusion still feature highly in the areas identified as Community Economic Development areas i.e. Easthouses/Mayfield, Woodburn and Gorebridge.

## **CHILDREN'S SERVICES IN MIDLOTHIAN**

32. The corner stone for children's services in Midlothian is the Children's Services Plan 2002-2004 and the Childcare and early years plan 2002-2004, both published by Midlothian Council.

33. The Children's Services Plan aims to take forward Government and Scottish Executive's long-term vision of a more just and socially inclusive society by promoting service development and greater accountability. The plan mirrors "Social Justice", in that it advocates long-term integrated planning and recognises that children's issues cannot be viewed in isolation from other welfare issues. One of the key principles is to maximise social inclusion. The plan is the responsibility of the Midlothian Children's Services Planning Group, who oversees a range of multi-agency sub groups. These groups contribute to the key defined areas of:

- Child safety and protection
- Transition to independence
- Child care and early education
- Child poverty
- Children with special needs
- Looked after children
- Raising achievement
- Youth issues including crime, substance abuse and health improvement

34. Clearly the provision of respite care services would enhance most of these areas, but nowhere in the plan is there an explicit reference to existing respite care policy, other than a passing mention that 33 families with disabled children had received some sort of respite service as at 31<sup>st</sup> March 2002. However, the plan identified, through two large focus groups held in April and May 2002, that parents of children with disabilities raised as one of their main concerns a need for flexible respite provision, "tailored to needs". They also expressed concerns over the need for greater availability of information on accessing services, sources of benefits, etc. The plan subsequently identifies, as one of its objectives, an increase to the number of families with disabled children receiving respite care services, but does not detail the extent or type of services envisaged. A subsequent section of this report will examine respite care for the disabled in greater detail. Midlothian Council Social Work

Services did however facilitate 12 families to benefit from a holiday week at the caravan provided by the Friends of Midlothian's Children. For all those involved this provided a break they would not otherwise have had and the service is highly regarded by Midlothian Council. On what basis the families were selected is not known.

35. The Childcare and Early Years Plan takes a dual role of reviewing work undertaken during 2001-2002 and outlining future work for the period 2002-2004. It details the main objectives that are part of the overall Midlothian Children's Services Plan. Midlothian Childcare and Early Years Partnership currently co-ordinate the provision of nearly 4000 childcare and early years education places for children up to the age of 14. Pre-school education is available for all three and four year olds whose parents request it. For younger children Midlothian Sure Start offers childcare and parenting support in five settings across Midlothian and caters for approximately 200 families per annum.

36. Working parents of primary school age children are assisted with after school and holiday care being provided by a network of afterschool clubs. Ten clubs provide 425 afterschool places for primary school age children on a term time basis, with 355 places available during the school holidays. Additionally, 116 pre-school places are provided, with one club offering provision for 12-14 year olds. 117 childminders make available 511 places for children in the Midlothian area. This represents an increase of 47% in the number of places available in afterschool clubs across Midlothian. The Midlothian Childcare Audit showed that 16.2% of respondents had been helped into full or part-time employment by the provision of affordable childcare. The needs of working parents are being further addressed through the development of wrap around care. Parents in the Penicuik and Bonnyrigg can buy additional childcare hours, which will link into the free pre-school education that three and four year olds already receive. It is planned to expand wrap around care to other areas of Midlothian.

### Conclusion

37. It is hard to draw any other conclusion than short break respite care is given a very low priority within the context of formal children's services planning in Midlothian. In conversation with key Midlothian Council staff (5) it was apparent, that while there was recognition of the value of short break respite provision, the council actually provided very little. The published childcare budget makes no provision for such services,

with the major effort being directed at after school clubs and wrap around services.

38. Similarly, the requirements of young carers are not addressed in either plan. However, in conversation with the staff of the Midlothian Young Carers Project, Children 1<sup>st</sup> (6), it became clear that Midlothian Council have ring-fenced £30,000 per annum, up to 2006, for the project. Including other contributions from the voluntary and private sectors Children 1<sup>st</sup> has an annual budget of about £100,000, which caters for up to 50 young carers a year. In this respect Midlothian Council can be regarded as enlightened as they are one of only very few local authorities to ring-fence money in this manner.

39. Midlothian Council have undertaken some market research and circulated 6,000 questionnaires to parents, on the demand for pre-school education and childcare for 0-16 year olds. The questionnaire had a return rate of 20%. Amongst other findings it was apparent that:

- Most respondents heard of childcare and early years provision by word of mouth and considered that there is too little information and would wish more information on the general availability of childcare. Respondents requested more childcare in particular in school holiday schemes, after school care and wrap around care.
- There is no mention of short break respite care but that is likely to be because the questionnaire did not invite comment on such a service.

40. Midlothian Council are in the process of developing a formal respite care policy but this is at a very early stage. They admit that they are unsure of the scale of the requirement and, indeed how to quantify it. This work remains ongoing.

## RESPITE CARE FOR FAMILIES WITH CHILDREN WITH LEARNING DISABILITIES

41. Much of the background research on the scale of the requirement for respite care for children with learning disabilities, and their carers is taken from the latest Scottish Executive policy initiative document on learning disability services in Scotland, “The same as you” (7). A useful definition of those with learning disabilities is as follows:

*‘A learning disability is a significant, lifelong condition which has three facets:*

- *Reduced ability to understand new or complex information or to learn new skills*
- *Reduced ability to cope independently; and*
- *A condition which started before adulthood (before the age of 18) with a lasting effect on the individual’s development.’ (8)*

42. There is not enough detailed information about the number of people in Scotland who have learning disabilities. However, research suggests that:

- 20 people for every 1,000 have a mild or moderate learning disability
- 3 to 4 people for every 1,000 have a profound or multiple disability
- There are 4,000 to 5,000 children and young people under 16 living in Scotland who need a lot of help with daily living

43. On the basis of the above, and by cross referencing with the population figures released by the General Registry Office for 0-17 year olds in the year 2000, it is possible to make the following tentative extrapolations:

- There are around 366 children with mild or moderate learning disability in Midlothian
- There are around 73 children with profound or multiple disability in Midlothian

44. Midlothian Council currently has 307 children registered as disabled (9), be it physical or mental. Research suggests that a high percentage, perhaps as high as 25%, of those with mild learning disability will not

have been registered with local authorities. According to the “Children’s Services Plan 2002-2004” there were 33 families receiving some form of respite service as at 31<sup>st</sup> March 2002, although the extent and type of service is not detailed.

45. There are two other trends, which are important to note. Firstly, research suggests that the number of people with learning disabilities will continue to grow by over 1% a year over the next ten years. And, more will live longer, so the needs of people with learning disabilities will change. Secondly, the vast majority of people with learning disabilities are no longer cared for in hospital but rather in the community. This recent and comprehensive change will impact greatly on both those with learning disabilities and their carers.

46. Research on respite care suggests that what is offered is directed more at carers’ needs rather than the needs of people with disabilities. Many families are unhappy with the term ‘respite’ and prefer to use ‘short breaks’, which shows that the services should be designed to meet both sets of needs.

47. Where families have access to a short break service they value it highly, but report that they rarely receive enough to meet their needs. There is no record of the numbers within this group who need or actually receive short breaks, and while it is clear that there is an overall shortfall in what is being provided, it is difficult to work out accurately by how much.

48. Clearly providing the finance for short breaks is difficult for local authorities. Since the trend for care in the community started many old services are being wound down and many new services developed. Local authorities, both for their own services and those they commission from (mostly) the voluntary sector, will not be able to manage and pay for old and new services at the same time. The Scottish Executive therefore propose a ‘change fund’ to which local authorities may apply for developing, amongst other things, short breaks for people with learning disabilities. In addition the Scottish Executive launched their strategy for carers in Scotland in November 1999. It means local authorities need to spend £10 million of their grant-aided spending for 2000-2001 on services for carers (including short breaks), that is £5 million from their present budgets and a further £5 million from the new resources made available in that year. It was felt this would lead to a real increase in short breaks.

## Saltergates School

49. Much of the above has been confirmed in conversation with Jean Loughlin; the head teacher at Saltergates School for special needs children (10). The school is based in Dalkeith and caters for 112 special needs children from Midlothian. She confirmed that there was a significant gap between what is available and what is required. Additionally, what is provided is often inconvenient and inflexible and she stressed the need for a respite service that was sufficiently flexible, such that it could be adapted to the needs of the child or the family, rather than them being made to fit in with what was available. She made the point that, as a child grows older their needs often change in regard to the amount of respite care they need, be it in greater or smaller amounts. In almost every case this was not reflected in the redistribution of services and it was felt that this detracted from both services to others and the flexibility of the system as a whole. Outside the remit of this report, but equally important, was the fact that once a child left school respite services almost entirely ceased to be provided and that this proved extremely dislocating for the families involved.

50. The point was also made that many parents of special needs children relied on family and friends for respite assistance and had never contacted the local authority for advice or help. Mrs Loughlin made the point strongly that there were families who received no help, but who were as equally in need of help as many of those who did, and the conclusion she drew was that there was no equality of service across the board.

51. Saltergates school families and children use a number of respite services, including social worker outings and evening, weekend or even weeklong breaks at NCH Gilmerton. They are very limited in the number of after school clubs they run since they do not have a budget to provide transport outside the normal school run times. This is identified as a major problem for the school. For 2004 they will take 4 weeks usage of the Friends of Midlothian's Children disabled caravan and 4 weeks usage of the existing caravan. They could take significantly more, perhaps up to 20 weeks, if it were available. Additionally the Friends of Midlothian's Children will pay for 44 weeks of respite care for 6 children at a purpose built home in East Lothian, which is run by the Aberlour Trust for East Lothian Council, there is no similar facility in Midlothian. The children will be picked up from Saltergate School by Aberlour Staff and taken to the home for a few hours, once a week. Afterwards they will be returned to their homes. This project is costing the Friends £10,000

and is a one off project for 2004. The charity will not be able to afford this kind of cost in 2005 and are currently in the early stages of looking at a programme of alternatives, possibly in partnership with Midlothian Sure Start. There is a long-term aspiration to provide a purpose built facility in Midlothian.

### Conclusion

52. There are currently 307 children registered as disabled in Midlothian. This includes both physical and mental disabilities but probably hides the true figure, since it is likely that as many as 25% of those with mild learning disabilities will not have registered with the local authority. It is conclusive, both from published research and from discussions with local experts, that where respite care is provided it is highly valued, but that there is a significant gap between what is available and what is needed. This is borne out by the fact that Midlothian Council provide some form of respite services for only 33 families, which suggests many families go without. Families also need a range of services that suit individual needs and that are planned, flexible and timely. Almost all the services provide by Midlothian Council are one to one respite care for a few hours only. The provision of short breaks is not a priority.

53. Money for respite care is proposed, both from a Scottish Executive 'change fund' and from a requirement for local authorities to ring fence finance for such services, including short breaks.

54. The need for respite care is likely to increase as the growth for children with learning disabilities is projected at over 1% a year over the next 10 years.

## YOUNG CARERS IN MIDLOTHIAN

55. It is difficult to accurately predict the number of young carers in Midlothian, as the council are only able to base figures on those young carers they know about. They recognise that there are likely to be many young carers who struggle on without help, thus compromising, to a greater or lesser extent, their education, friendships and often mental and physical wellbeing as they struggle to cope with the burden of care at home. Trying to predict the size of this invisible community is extremely challenging. There remains a perception that respite care is concerned with 'older people' only. The 2001 census identified 285 registered young carers aged under 18 in Midlothian.

56. Set against a Scottish average of 36.6% of households with one or more persons with a limiting long-term illness Midlothian has an average of 36.12%. However, this hides the fact that Dalkeith/Woodburn (44.69%), Easthouses/Mayfield North (43.45%) and Newtongrange (41.92%) all have significantly higher figures than both the national and regional averages. Since there are no figures available for average household size in Midlothian it is not possible to extrapolate these percentages into numbers, much less predict what proportion of that figure are carers under the age of 18. It is known that in August 2002 4,600 people claimed Disability Living Allowance and 500 people claimed Severe Disability Allowance in Midlothian (11).

57. What is clear is that the number of young people required to provide care for a family member is likely to rise for the following reasons:

- The percentage of people born with a disability is increasing at a forecast rate of just over 1% a year for the next 10 years
- People with disabilities are living longer
- The move from institutionalised care homes to care in the community has gathered pace and will not be rescinded
- Carers and the cared for now have a much greater say on the services they want and how finances should be spent

58. In Midlothian the focal point for young carers is the Young Carers Project, based in Dalkeith, and run by Children 1<sup>st</sup> (paragraph 38 refers to the financing of the project). The project was established in May 2001 and provides a range of services for young people aged between seven and 21, who provide physical or emotional support for family members experiencing problems with mental health, physical disability, drugs or

alcohol. Since the project started it has received 65 referrals and can cater for up to 50 young people per year. It currently has a waiting list of about five, although the full extent of those providing care is not reflected in this figure, as this figure only identifies those young carers who have been adopted by the project and are awaiting a place. Children 1<sup>st</sup> suggest that, based on nationwide figures and research done on other specific areas, there may be as many as between 300 and 500 young carers in Midlothian. The largest group looked after by young carers, and helped by Children 1<sup>st</sup> were those with mental health problems followed by, and in order, those with mixed alcohol and mental health problems, those with drug and alcohol problems and those suffering physical disability.

59. Referrals come from a combination of professionals, the cared for and self-referral by young carers. The project offers confidential individual support, which gives young carers the opportunity to discuss and better understand their situation in private. They are also able to chose from a range of activities, such as workshops, discussion groups, art and drama and fun days out. These are particularly important as leisure facilities in Midlothian are at best very limited. All these activities are designed to offer young carers the opportunity to share experiences, gain knowledge and develop supporting relationships.

60. A fundamental part of the project's activities is using the respite service provided by Friends of Midlothian's Children. In 2003 they were allocated 6 weeks usage of the caravan at Berwick-Upon-Tweed, which provided short breaks for 14 adults and 15 children. In conversation with the project officer (12) he made it clear that they valued the service greatly and ideally would wish for a minimum of 12 weeks usage per year, which would allow the majority of the young carers involved in the project to take a short break. He particularly liked the fact that the Friends of Midlothian's Children were a 'brokerage service' only and thus provided the service but did not get involved in the selection process, allowing him complete independence of action.

### Conclusion

61. There are no exhaustive figures available for the number of young carers in Midlothian. However, Statistics suggest that it is likely to be many more than the 50 or so catered for each year by Children 1<sup>st</sup>. The scale of the service provided by Children 1<sup>st</sup> is limited not by the scale of the problem but by their budget. The stresses that young carers experience are widely recognised and respite care is an essential part of the suite of services that they require. Children 1<sup>st</sup> regard respite services

as extremely valuable and could easily double the amount of weeks they take from the Friends of Midlothian's Children.

62. Many of the conclusions made in the last chapter are equally relevant here; namely, the requirement is likely to increase in the coming years, respite services provided by the local authority are scarce but money should be coming on line for such provision via Scottish Executive direction and funding.

## **MIDLOTHIAN SURE START**

63. Midlothian Sure Start is a voluntary organisation that provides community-based, family focused resources, including high quality childcare and direct support to parents. The project provides support, which is targeted at areas of greatest need including innovative outreach to families not otherwise likely or able to seek such services. The service is aimed at, predominantly, families with children under the age of three. Although many of these families have additional children who range in age. Families attend Sure Start centres as a result of their difficulties in coping with a number of stressors, including special needs of a family member, post natal depression, mental illness and drug and alcohol problems. The underlying factor in the majority of cases is poverty. 90% of those helped by Sure Start are in receipt of some form of benefit and around 40% are receiving income support and are regarded as extremely deprived. Around 50% are single parent families (13). Referral is by a combination of GP's, Community Nurses, Housing Officers, Social workers and self-referral. Spaces are provided on a first-come, first-served principle, although the project manager has the provision to allocate help on the basis of priority need.

64. The project has five centres. There are full time centres at Penicuik ('Stepping Forward') and Mayfield ('Family Reachout') and part-time centres at Bonnyrigg ('Positive Steps'), Gorebridge ('Small Steps') and Woodburn ('Hand in Hand'). The full time centres open on Monday to Friday between 9am and 4pm. The part time centres are open for 20 hours per week each. It should be noted that the part time centres are part time, not because of the scale of need but because funding does not exist to allow these centres to operate full time. Demand for places at the part time centres is correspondingly very large and continues to grow to the extent that demand far outstrips supply. At Woodburn and particularly at Bonnyrigg accommodation is insufficient

65. Midlothian Sure Start is a voluntary organisation, funded by Midlothian Council, NHS Lothian, and receives other support from organisations such as Cybil, The Pleasance Trust and the Friends of Midlothian's Children. They also fund raise. Funding has been an ongoing issue and during 2002-3 they had to use a significant amount of their financial reserves in order to maintain all their current services. However this has been counter-balanced by a commitment, by Midlothian Council, of an additional £70,000 annually for the period 2003-6.

66. Sure Start work with approximately 200 families per annum. For the period 1<sup>st</sup> April 2002 to 31<sup>st</sup> March 2003 the project offered direct support to 202 adults and 269 children. Over the same period the two full time centres assisted, through partnership working, another 124 children and adults. The project offers a wide range of services that include:

- Support for the whole family including grandparents and other primary carers
- Child development by learning through play
- Co-ordinated self help groups
- An advocacy service
- A counselling service
- Crisis intervention
- Support from home
- Joint child/parent initiatives
- Therapeutic group work
- Parenting skills courses
- Complementary therapy courses
- Project user groups
- Way forward programmes
- Personal development programmes
- Career information sessions
- Life skills information
- Assertiveness and confidence building courses
- Anger management

67. The project also run a limited programme of outings, to places such as Pease Bay and Vogrie and in 2001-2 around 200 parents and children attended such days out. The Friends of Midlothian's Children provide their only other short break provision and it is very highly valued. To date 20 families have benefited from such holidays and this year Sure Start were allocated 6 weeks usage of the caravan at Berwick-Upon-Tweed, which allowed 13 adults and 20 children to enjoy a holiday. This is barely adequate for their needs and they estimate that they could take at least 20 weeks of the existing caravan and 5 to 10 weeks of the disabled caravan. It should be noted however that a major issue for the families being offered a short break is the, often prohibitive, cost of transport to and from Berwick-Upon-Tweed.

## Conclusion

68. Midlothian Sure Start works with around 200 families a year. These families suffer from a number of stressors. However the underlying factor in the vast majority of cases is poverty. 40% of those helped by Sure Start are regarded as extremely deprived.

69. It is important to note that the three part time centres are part time, not because of demand but because of a lack of funding. Demand for places at the part time centres far outstrips supply. Funding is a constant concern although Midlothian Council have recently committed £70,000 per annum for the period 2003-6.

70. The provision of short breaks by the Friends of Midlothian's Children is very highly regarded by the project and is the only holiday that those families get. It provides an essential break from normal routine and environment. Sure Start estimate that they could easily fill 20 weeks of the existing caravan and 5-10 weeks of the disabled caravan. However, both the availability and cost of transport to and from North Berwick is a major issue.

## CASE STUDY

Mary (name changed) moved to Mayfield 3 years ago from the north of England with her partner and 2 children, aged 10 and 7 years old. She had another child 2 years ago and a fourth 8 months ago. She struggled to cope with the extra workload, found it extremely difficult to make friends and had no family support system to provide help and advise. She became isolated and depressed and was eventually referred to Midlothian Sure Start by the mental health nurse at her local health centre.

Sure Start offered her a lot of help and advice and she was able to make friends with other mothers from her area. She was also able to benefit from a weeks holiday for the whole family, provided by the Friends of Midlothian's Children. This was the first holiday the family had taken together. Without the assistance of the Friends there was no prospect whatsoever of the family taking such a break. The family benefited enormously from the experience and "felt a massive boost" as a result. They were able to spend quality time together, away from their normal environment, for the first time since moving to Scotland. The family travelled to and from Berwick-Upon-Tweed by train, which with four young children was stressful, time consuming and expensive.

## **RECOMMENDATIONS**

71. It is apparent that the provision of respite care in Midlothian needs a higher profile. The Friends of Midlothian's Children may wish to consider ways in which this may be achieved. One possibility is to seek membership of the Midlothian Childcare and Early Years Partnership. The Partnership was set up in 1999 with the aim of bringing together people from organisations with an interest in child care and pre-school education and out of school provision. Representatives from Education, Community Services and Social Services Divisions of Midlothian Council, local health services, the voluntary sector, private nurseries, the business community, further education and employment service meet regularly to plan the services already provided and to identify the need or new services. The aim of the partnership is to develop affordable childcare and pre-school education services which meet the needs of children and parents and are available across Midlothian. It must be recognised, however that any attempt at lobbying would be regarded as a 'political' act and would suspend the Friends of Midlothian's Children position as a brokerage only service.

72. The extent of the requirement for respite services has been highlighted by this document but exact figures remain elusive. The size and needs of the 'invisible' community need to be quantified and this can only be done by a detailed market research exercise using a statistically significant sample population. This would be expensive and time consuming but would provide accurate and quantifiable information.

73. A recurring theme throughout this study has been the very real problems encountered with the cost and availability of transport to and from Berwick-Upon-Tweed. Additionally Saltersgate School are able to run only very limited after-school clubs because the costs of transport are prohibitive. The Friends of Midlothian's Children may wish address this issue.

74. For next year the Friends of Midlothian's Children will provide 32 weeks usage of the existing caravan and six weeks usage of the proposed disabled caravan. This report has highlighted a minimum desired requirement of 62 weeks and therefore easily justifies the acquisition of a further caravan, if funds allow. This does not take into account the needs of the 'invisible' community, mentioned earlier in this report.

75. For 2004 the Friends have bought a package of respite care from the Aberlour Trust for 6 children with special needs. The Aberlour Trust run a purpose built centre in East Lothian, there is no similar facility in Midlothian. This is a one off project, which will cost £10,000 and will not be repeated in 2005. The Friends are currently looking at alternatives, possibly in partnership with Midlothian Sure Start, for 2005. There is a long-term aspiration to provide a purpose built facility in Midlothian and pursuing this should become a key factor in the Friends strategic planning.

## **FOOTNOTES**

1. [www.Scotland.gov.uk/library2/doco7/sjmd-oo.htm](http://www.Scotland.gov.uk/library2/doco7/sjmd-oo.htm).
2. “Poverty wrecks futures”. Published 12 November 2003.
3. The report identifies 320,000 children being in families who survive on less than the poverty line figure of £242 a week.
4. Much of the statistical analysis comes from the Socio-demographic profile of Midlothian 2003. As yet much of the data used does not reflect the new electoral ward structure in Midlothian, effective from 6<sup>th</sup> May 1999.
5. Norman Glennie. Operations Manager Children and Families and Criminal Justice. Christine Schaffer. Children’s Services Planning Officer.
6. Rob Bayne. Project Officer Children 1st. Rob Bayne has now left his post and has yet to be replaced as of 27<sup>th</sup> November 2003.
7. “The same as you”. Published by the Scottish Executive 2003.
8. “Learning Disabilities – the fundamental facts”. Published by the Mental Health Foundation 1993.
9. Figures provided by Christine Schaffer.
10. Interview with Jean Loughlin. 19<sup>th</sup> November 2003.
11. Socio-demographic profile of Midlothian 2003.
12. Rob Bayne. 11 November 2003.
13. Cheryl Brown. Project Manager Midlothian Sure Start. 10<sup>th</sup> December 2003.

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2. *Social Justice...A Scotland where everyone matters*. Annual Report 2002. Published by the Scottish Executive.
3. *Getting our Priorities Right. Good Practise Guidance for working with Children and Families affected by Substance Misuse 2002*. Published by the Scottish Executive.
4. *The same as you. A review of services for people with learning disabilities*. Undated. Published by the Scottish Executive.
5. *Midlothian Social Inclusion Partnership Community Economic Development Plan Final Report August 2001*. Published by Community Enterprise Ltd.
6. *Midlothian Council Childcare and Early Years Plan 2002 – 2004 and Children’s Services Plan 2002 – 2004*. Published by Midlothian Council.
7. Midlothian Sure Start Annual Reports, 2001 – 2002 and 2002 – 2003.
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10. *Learning Disabilities - the Fundamental Facts 1993*. Published by the Mental Health Foundation.
11. *Breaking New Ground – rethinking respite provision in Edinburgh 2000*. Published by the City of Edinburgh Council.
12. Answers to Parliamentary Questions S2W-4621 to S2W-4828 asked on behalf of the Friends of Midlothian’s Children by Rhona Brankin, MSP for Midlothian. 12<sup>th</sup> January 2004.