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Title of paper: Local Area Co-ordination: Strengthening support for people with learning disabilities in Scotland

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Local Area Co-ordination: Strengthening support for people with learning disabilities in Scotland

Accessible Summary

- Local Area Co-ordination is a new, person-centred way of supporting people with learning disabilities and their families to have a good life in the community.
- There are 59 local area co-ordinators (called 'LACs' for short) in Scotland.
- There are a lot of differences in the way these LACs work; for example, whom they work for, how many people they support, whether they support children or adults and how much money they are paid.
- People with learning disabilities and their families really like their LACs. They feel the LAC is on their side.
- LACs have helped people in lots of ways, like finding supports and services, getting a paid job and moving house. They help people join new groups and meet people.
- We think the Scottish Executive should pay for more LACs in Scotland and write new guidelines about how to do local area co-ordination.

The background to local area co-ordination

Following its review of services to people with learning disabilities, the Scottish Executive (2000) published a report entitled *The same as you?* Among its 29 recommendations was a proposal that local authorities and health boards introduce local area co-ordination, something which did not feature at all in the equivalent document - *Valuing People* (DH 2001) – south of the border. Local area co-ordination was described as an innovative, person-centred way to support people with learning disabilities and their families to build a 'good life'. It was first developed in Western Australia in the late 1980s in response to long-standing difficulties providing services to people with learning disabilities living in remote areas. Disability Services Queensland (2001) described the key elements of local area co-ordination as follows:

- The quality of the relationship between a local area co-ordinator and the individuals/families with whom they work
- Working with families and individuals across all ages and life stages and all types of impairment
- A focus on developing and maintaining informal supports, natural social networks and facilitating access to mainstream services
- Community building
- A local community base, community connection and geographic boundaries, defined by place
- A supportive management framework
- An agreed value base and set of principles as the basis of decisions and actions.

Introducing local area co-ordination to Scotland was part of a wider vision set out in *The same as you?* that people should be valued, respected and included within their communities, lead full and active lives and have choices and opportunities to realise their potential. It was initially envisaged that, among other tasks, local area co-ordinators (LACs) would each support about 50 individuals and families⁴ to build up strong networks, work across traditional service

⁴ In line with the local area co-ordination ethos, in this paper people with learning disabilities and their carers are usually referred to as 'individuals and families' rather than 'service users'

boundaries, work with other agencies and local community groups to promote inclusion and act as an information point. Unlike *Valuing People*, *The same as you?* was not a White Paper and, arguably, had less force: local authorities were encouraged, but not obliged, to implement local area co-ordination.

Study aims and methods

The Scottish Executive commissioned the Social Work Research Centre at Stirling University to carry out an independent evaluation of the implementation of local area co-ordination. This 11-month study had three aims - to examine the lessons from implementation across Scotland, to explore, in broad terms, the outcomes of local area co-ordination and to assess the scope for its future development.

Five different methods of data collection were used to address these aims. First, a (Scottish) policy and (international) research review was conducted. Restricted space prevents reporting these findings here: suffice to say that, with the exception of some notable Australian studies (Bartnik 2003; Chadbourne 2003; Chenoweth and Stehlik 2001), little research has been carried out on local area co-ordination. Secondly, a questionnaire was emailed to all LACs in post across Scotland, seeking basic 'factual' information about their jobs. There are 32 authorities in Scotland and, by March 2006, 25 had appointed at least one LAC. Forty-four (out of a total of 59) LACs completed and returned these forms, representing 24 of the 25 local authorities with local area co-ordination projects⁵. These data were analysed using SPSS. Thirdly, in order to explore policy and practice issues in more depth, semi-structured interviews were conducted with LACs in the same 24 authorities. At the end of the email questionnaire, LACs had been asked if they would be prepared to take part in an interview and, whenever we received a positive response, we contacted that person to arrange an interview. At this point, we asked the individual to check whether the other LACs in his/her authority (if there were any in post) also wished to participate, in which case a joint interview was conducted. In all, 35 LACs took part in these interviews. We do not know if those LACs who chose not to be interviewed did so because they thought that one respondent was enough to represent their authority or for some other reason which may (or may not) have been related to their views about LAC. (The interview was piloted in one authority which had five LACs but, because it was a 'trial run', only one LAC, with a supervisory remit, was invited to take part). Fourthly, in order to examine management issues and perspectives, it was decided to interview managers in half the authorities which had local area co-ordination. These authorities were randomly selected (choosing every other authority on an alphabetical basis) and we also alternated between interviewing LACs' line managers (mostly middle management) and those with responsibility for making decisions about LAC in the authority (senior managers). All the managers approached agreed to participate. In all, 14 managers from 13 authorities took part, (including two from one authority which, unusually, had two separately run projects). Data were tape recorded with respondents' permission and transcribed prior to being subject to a content analysis.

Fifthly, case studies of local area co-ordination in practice were carried out in four authorities, selected to enable examination of local area co-ordination in a rural setting, an urban setting, the voluntary sector and across traditional service user boundaries. The case studies also explored progress in community capacity building. They provided an opportunity to explore service users' views and to gather evidence about the outcomes of local area co-ordination for individuals, families and communities. Each area was visited by two members of the research

⁵ One local authority declined to take part in the study, but did not say why.

team for two to three days, using an approach based on that developed in a review of day opportunities for people with learning disabilities (Cole *et al*, 2007). Using a mixture of observation and interviewing, topic guides were developed for LACs, managers, service users, parents/families and community groups. The visits were organised on our behalf by the LACs and we were not aware of any individuals or families declining to take part. Some people volunteered to be included in the case studies when they heard about the research.

Information sheets and consent forms were sent to potential participants. Those for families, service users and community groups were passed on by the LACs; we only knew the names of those who agreed to take part. All data were treated as confidential. The real names of service users and their families were not used in any reports, although it might be possible to identify the LACs in the case studies, since these authorities were, with their agreement, identified.

Finally, telephone interviews were conducted with all seven Scottish authorities which had chosen not to implement LAC at that point. These discussions focused on the reasons for that decision and their alternative strategies for supporting people with learning disabilities. We cannot report all the results in this paper: see Stalker *et al* (2007a) for a full account or Stalker *et al* (2007b) for a summary of the main findings. An illustrated accessible summary, circulated to people with learning disabilities who participated in the study, is also available (Stalker *et al* 2007c). In the rest of this paper, we present some key findings about implementation, the local area co-ordination process and its main outcomes.

Extent and nature of implementation

Coverage of local area co-ordination across Scotland is patchy and uneven, with considerable variation in the size of the areas covered by individual LACs. Most were employed by local authorities but three authorities had commissioned voluntary agencies to provide local area co-ordination and one LAC was employed by an FE college. In a fifth area, the local authority and NHS Trust were joint employers. Over half the LACs were located in social work offices or resource centres for adults with learning disabilities. Overall this was seen as a disadvantage, because local area co-ordination is intended to be independent of statutory provision, especially care services. This is partly so that LACs can act as independent advocates for people using such services but also because it is part of the local area co-ordination ethos that, where possible, individuals move beyond the role of welfare recipients. A few LACs were satisfied with their bases, such as a local shop front, a leisure centre and a terraced house.

All the LACs supported adults with learning disabilities and those in 19 authorities also worked with children with learning disabilities. Besides working with adults with learning disabilities, nine authorities also supported people with Autistic Spectrum Disorder and a further five, people with mental health issues. Only three had a remit to work with people with physical or sensory impairment as well as those with learning disabilities. However, within these apparently broad categories, some LACs had specific remits; for example, to work only with youngsters with learning disabilities aged 14 to 19, or those aged over 45 living with parents. Only 12 of the 24 authorities interviewed offered a 'cradle to grave' service, supporting people of all ages. Where this was so, LACs reported great advantages in being able to continue working with people during periods of transition while parents and children were able to benefit from the local area co-ordination approach as early as possible. Where the remit was age - or issue-specific, however, LACs, found it frustrating having to turn away people who were not eligible for support. This was seen as contrary to local area co-ordination principles about inclusion.

LACs in 11 authorities had a dedicated annual budget to support their work: in the majority of cases this was under £5000. These funds were used, for example, to enable individuals and families to access resources, to promote inclusion or independence, provide 'one-off' support for service users, pay volunteer expenses, or purchase resources or equipment for the LACs. Of those who did have a budget, just over half considered it adequate to meet their needs.

There was significant variation in the levels at which LACs were appointed and remunerated. Some carried management responsibilities and were experienced practitioners, while others were recently qualified or new recruits into the 'caring' professions. Nevertheless, many LACs felt there should be greater consistency across Scotland in the terms and conditions applying to local area co-ordination posts.

The local area co-ordination process

The most common way for LACs to identify individuals and families to work with was through informal 'introductions', rather than referral, by other agencies, although word-of-mouth and self-referrals also played a role. Several LACs stressed that they only worked with people at the latter's invitation. However, a few authorities required people to pass through social work referral and allocation systems to access local area co-ordination support.

The number of people LACs worked with ranged from two to 47 families and from one to 42 individuals. This diversity partly reflects the fact that LACs had been in post for varying periods of time but in addition, authorities had differing approaches. Overall, a high proportion of time was spent in direct contact with individuals and families and, to a lesser extent, networking with community groups, with many LACs feeling that spending time in meetings or on paperwork was not appropriate to the role. According to LACs' estimates, on average they spent 37% of their time working with individuals, 25% with families, 13% with community groups, 7% on administration and 2% on other tasks. Typical activities identified by one LAC manager included accompanying people to appointments or chosen activities, doing 'follow-up' work in the office, liaising with other professionals and providing disability awareness training.

An important part of local area co-ordination is its strong value base. It was clear from what individuals and families told us that, without exception, they greatly valued the person-centred style of local area co-ordination and the sense that the LAC was 'alongside' the family:

I could boil it down in a couple of words: Basically he's on our side. He doesn't question what we say; he doesn't question the validity of my son's opinions on anything. He's there for him and he's the only one who's there for him. He's not on the school's side, the council's side, he's not on anyone's but my child's side (*mother of boy on autistic spectrum*).

Individuals and families commented on the tenacity with which LACs went about their business. This could involve challenging other agencies to meet their responsibilities or looking for a creative way to meet an unusual need. The LACs were widely seen as taking a positive, holistic view of individuals' situations. One LAC manager reported:

One 80 year-old that I met who had a 45 year-old Down's Syndrome son said to me quite early on, she said, 'you are the first person that has come into our lives that has talked positively. All my life professionals have said to me 'no, no, no, can't, can't, can't''.

Local area co-ordination outcomes

Most of the findings about outcomes are based on the four case studies. As noted above, these authorities were chosen to allow exploration of specific aspects of local area co-ordination. In addition, three of the four were well established and relatively well staffed projects which had been in place for some years. Thus they were not representative of local area coordination across Scotland, a point which should be borne in mind when reading this section.

A number of positive outcomes for individuals and families were identified from the local area co-ordination process in these areas. First, LACs had helped people **access a wide range of supports and activities**. Besides health and social care services, these included alternative accommodation, including tenancies, and various work, training and education opportunities. Several LACs supported people to gain the confidence needed to extend their horizons, venture outside their safety zone and try something new; for example, one young man said to have spent the 'best part of the previous three years in his bedroom' was now attending college.

Secondly, there was some evidence of **more people having access to support and services**. LACs worked with individuals and families who either fell short of the criteria for more formal support, perhaps because they had 'mild' learning disabilities or appeared to be living independently, or else already had some source of support. However, these included vulnerable, lonely individuals, such as those living on an inner city estate who were harassed by neighbours and required considerable sustained support to improve their quality of life.

Thirdly, the findings indicate that, following local area co-ordination interventions, **people were now better informed** about options for support, both formal and informal. A few individuals reported that LACs seemed to have more time than other workers to seek out information and, importantly, to explain how the information applied to individual circumstances. People said that, as a result, they felt less confused and had a better understanding of services.

Fourthly, better information resulted in **people having more choices**. As well as telling people about possible options, LACs often accompanied them to groups or activities for a 'taster'. One LAC commented that growing capacity led to increasing choices because finding a solution to one person's issue could widen the known options for others.

Fifthly, with LACs' support, people were enjoying **increased social activity, friendships and relationships**, with individuals becoming more involved in community activities and groups. For example, one man with learning difficulties introduced to a bowling club now found that club members stopped to chat to him in the street.

Finally, there were many examples of **increased availability of flexible supports**. In one rural authority, LACs had helped groups apply for funds to develop inclusive leisure and recreational activities as an alternative to day care. A local leisure centre had agreed to set up a scheme whereby carers could accompany people free of charge. It was suggested that greater use of mainstream services made people realise they did not need to rely so much on formal provision. A striking example was of a man introduced to a supported employment scheme who found a paid job: his care package reduced from 50 to 5 hours a week.

Fewer outcomes were identified for community capacity building, with most LACs reporting little progress in this regard. Nevertheless, it was seen as a priority for future work, and was the area most often identified as a training need. Reasons cited for lack of progress included:

- LACs being based outside the areas they worked in
- LACs having no drop-in facility
- apathy/resistance in some communities
- lack of 'spare' resources within disadvantaged communities
- the long-term nature of community capacity building.

However, LACs in six authorities had made considerable in-roads in community capacity building. Factors which may have contributed to progress included:

- LACs having bases other than social work offices
- reported goodwill in communities and a readiness to get involved
- LACs having previously worked in the area in another capacity, in three cases with a community development remit
- A clear understanding of the value of community capacity building, its place within local area co-ordination and a decision to prioritise it.

Our *impression* was that the last of these points may have been most significant.

Where community capacity building was under way, there were reports of **increased awareness of disability issues among local communities**. People had become more visible as a result of using mainstream services and community groups had a more inclusive ethos. Examples included a project whereby people with learning disabilities were creating a sensory garden as a local community resource, a community café where individuals were trained in catering and which proved popular with locals, and a community centre which explored new ways of including people with learning disabilities. There was also some evidence of **leadership development among individuals and their families**. In one area, members of a self-advocacy group were paid to deliver disability equality training to frontline staff in several settings. Elsewhere, people with learning disabilities participated in giving presentations to professionals, local communities and schoolchildren.

Discussion

In assessing the implementation of local area co-ordination across Scotland, a number of strengths have been identified. LACs showed great commitment to their role and to the people they worked with. Individuals and families appreciated the LACs' informal, person-centred approach and the time they spent building up relationships. Most LACs aimed to help people identify their own needs and work towards change over time rather than doing everything for them. The evidence of good outcomes in some authorities is encouraging. Individuals and families were unanimous that LAC had made significant improvements in their lives. Staff in other agencies commented on the increased self-confidence and well-being they saw in people benefiting from this new form of support.

At the same time, evidence about outcomes was mostly derived from the four case studies. These were not selected to be representative of local area co-ordination across Scotland but to illuminate aspects of implementation in different contexts. While some authorities had made broadly similar progress to the case study areas and, it may be speculated, were yielding

broadly similar outcomes, other areas were less advanced, particularly in relation to community capacity building. This is a long process and it is relatively early days, but our interviews with LACs and their managers suggested that in some areas LACs were spending most of their time doing intensive one-to-one work with a small number of individuals and families, leaving little energy left for community capacity building. Another risk associated with this approach is that individuals and families might become dependent on the LAC rather than developing their own capacity. The LAC role is intended to be an enabling one and it was, in our view, those LACs with a background in community development work who appeared most successful in this regard – and they were well represented in the case studies. Therefore the findings about outcomes should be read as evidence of what local area co-ordination *can* achieve when it is relatively well supported, resourced and understood rather than representative of what is actually being achieved at present across Scotland.

The study also revealed a number of tensions surrounding local area co-ordination. There is considerable variation in many aspects of implementation. These include size of area covered, actual and target populations, introductions, numbers, groups and ages of people supported, office location, access to dedicated budgets and grading. While there may be good operational reasons for variation at local level, there was concern among some LACs that these differences resulted in a dilution of or even, in some cases, departure from the key ethos. Others believed it was necessary to be pragmatic: an approach developed in remote Western Australia would need to be adapted in order to work in Scotland where the cultural, structural and political context is different. For example, Scotland has a much better developed service infrastructure and historically has taken pride in its public provision to meet social need. There is a need to consider how best to develop local area co-ordination without risking a reduction in the provision of health and social services to those who require them. Similarly, local area co-ordination places great emphasis on the role of families in supporting individuals but there are situations where this may not be feasible and/or desirable.

Another tension in the implementation of local area co-ordination is the ambivalence expressed by senior managers in some local authorities. While most were welcoming of local area co-ordination in principle, there were real concerns about the difficulty of managing scarce resources across a range of services, with local area co-ordination sometimes being seen as 'the icing on the cake'. Indeed, some managers thought that the money used to employ LACs might be better spent providing more social workers. One authority had given its care managers for people with learning disabilities a new job title - they were now called LACs - but, for the most part, were still doing care management.

If Scotland is to embrace local area co-ordination, and provide more equitable support across the country, then the number of LAC posts needs to be greatly increased. To achieve this and to overcome concern about limited resources in some areas, ring-fenced government monies to finance new posts and to support a national training programme should be considered. There is a need for updated guidance on implementing local area co-ordination, clearly setting out its ethos and values, and providing practical guidelines on its operation in a Scottish context. This could be supported by the creation of a National Development Worker post to promote the development of local area co-ordination across Scotland.

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