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**Regional Development for Inclusion: Community
Development and Learning Disabled People in the
North West of England**

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Regional Development for Inclusion: Community Development and Learning Disabled People in the North West Of England

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Introduction

The UK has a long tradition of democracy and participation in civil life. Since 1979 (the election of the Thatcher Government) this participation has been eroded and increasing numbers of people are excluded from the mainstream of civil life, have no homes and are dis-enfranchised. There is debate about whether social exclusion¹ exists, with some commentators suggesting that

“the concept of social exclusion as it is currently deployed places people either inside or outside the mainstream society, synonymous with outside the labour market.....the real society is that made up by the whole 100%, in which poverty is endemic..” (Levitas, 1996 p. 19)

Certainly, recent reports have shown how poverty, inequality of wealth and opportunity for full participation in civil life in Britain has increased (JRF 1995 a, b; across the geog divide). However, these debates have made little mention of disabled people (Beresford and Green, 1996), and it is more than poverty that excludes disabled, and learning disabled people in particular from participation. Their exclusion - and potential for inclusion - is intertwined with the history and practice of welfare organisations, and political and social attitudes, beliefs and behaviour (Burton and Kagan, 1995). Nevertheless, over the past 20 years a movement for inclusion has developed. National (and international) coalitions for greater participation by disabled people in general, and learning disabled people in particular, have been formed, moving towards the inclusion of learning disabled people in ordinary life, counter to some of the other social trends (Burton, 1983; 1989; 1996). In the North West of England, this movement has had a number of distinctive features, all of which have operated to aid the task of inclusion. The task has essentially been one of multi-layered community development (Amado, 1993; Atkinson and Ward, 1986; Burton and Kagan, 1995; Henderson and Armstrong, 1993; Pearpoint, 1990; Schwartz, 1993; Shearer, 1986; Tyne 1988;) characterised by conflicts and conflict resolution throughout. Despite the progress that has been made, it will be argued that some communities² are still not competent in including people with learning impairments, and that more effort and resources need to be directed to bringing ordinary people who have not had the opportunity to meet learning disabled people before, into the movement for change.

This paper will focus on the work of a small regional development team in the North West of England in helping to resolve some of the conflicts that have emerged over the past 15 years. I will describe the context in which the team works and the methods we use to contribute to and create principled social change and inclusive communities. The task is a complex one, and this discussion will necessarily be selective. I will outline some of the conflicts of interests in the development of inclusive communities, and their historical background. In outlining the complex nature of the context of the community development task, I will identify the causes of conflict and some of the main antagonists. In particular I will highlight the interrelated conflicts between learning disabled people, their families, local communities and welfare organisations. I will describe some of the community development strategies used by the small Regional development resource, that seek to change the balance of power between antagonists and help communities become more competent at including learning disabled people. The main strategies to which I will be referring are

- forming and sustaining alliances;
- increasing knowledge and understanding; and
- representation of interests.

These strategies all contribute to an overall process of empowerment (Burton and Kagan, 1996). I will illustrate some of the outcomes for learning disabled people themselves, their families, local communities and welfare organisations. Lastly I will draw out some of the implications for local community development within a Regional strategy, particularly in terms of social inclusion, management of conflicts of interest and timescales for change.

The context of the North West Training and Development Team

Geographical Context

The North West of England is the geographical area of Cheshire, Greater Manchester, Merseyside, Lancashire and South Cumbria (population pool, approximately 8 million). This area is the administrative area of the North West Regional Health Authority, which itself subsumes 16 Health Purchasing Authorities, 62 Health Provider Trusts and 22 local government authorities. It is within these boundaries that the North West Training and Development Team operates, and it is the work of this team that I will be referring to throughout this report, although I will be referring in the main to the period of work between 1986 and 1995, when the geographical boundaries of the Team were different, and included only Greater Manchester and Lancashire (19 Health Districts and 11 Local Authorities) with a population pool of approximately 5 million³. *Appendix I outlines the work of the Team.*

Policy and Historical Context

Whilst prevalence of people with learning impairments is difficult to gauge accurately, it is estimated that there may be 120,000 adults in England with severe and profound learning impairments⁴. Thus, most learning disabled people cannot live independently without support. Whilst the major providers of this support, even into old age, are people's families, the other major providers are welfare agencies⁵, primarily health and social service agencies. The kinds of supports will vary from the provision of day services, therapeutic interventions, support for employment, to 24-hour staffed accommodation and supervision.

In the North West a strategic policy document outlining the further shape of services in Greater Manchester and Lancashire was developed and signed up to by all contributory health and social services (Kagan, 1997; NWRHA, 1983). This policy, known as the Model District Service, provided the strategic framework within which the Development Team was constituted and was to work. It envisaged a future wherein learning disabled people would lead ordinary lives, like the rest of us, and participate in the same social institutions (Kings Fund Centre, 1982). The policy framework was re-affirmed and revised in 1989 (NWRHA, 1989), and still guides organisational change, regionally.

In 1984, approximately 3,100 learning disabled people lived in long stay mental handicap hospitals, usually located in the countryside away from other people. These hospitals were 'total institutions' (Goffman, 1961) insofar as they had all facilities for daily living and working on site. Part of the Model District Service strategy, in line with Government policy⁶, was to close the hospitals and return people to local living.

Today (April, 1997) 233 people live in the one remaining hospital in the Region. In 1989 there were still 4,500 staff employed in the large hospitals (NWRHA, 1990b). Currently there are 1,350 working in the one remaining hospital. If the hospitals were to close, then families would not have access to them for long or short term care of their learning disabled members. Staff would have to be re-deployed. If ordinary living was suitable for people in hospitals, it was also considered suitable for people living in other congregate settings, such as hostels. Between the period 1985 - 1993, the number of hostels in the region reduced from 60 to 38, and approximately 600 people moved from hostels into domestic scale accommodation - 400 of them between 1990 and 1992 (Kagan 1992a; NWTDT, 1992c). Approximately 300 staff working in hostels have been re-deployed. If hospitals and hostels closed, those people living in them, over a relatively short period of time, would be moving back to ordinary houses, in ordinary streets, next to ordinary people. So, over a period of 13 years, more than 3000 learning disabled people have moved into local communities, and 2,450 staff have either retired, left the service or been re-deployed into community services.

Stakeholder Context

If we stop to think about this, we can see clearly who the antagonists in the development process might be, but the nature of the conflicts were complex and not clear cut. Learning disabled people, themselves, were keen to move out of hospital (Walker, Ryan and Walker, 1983). Some family members of learning disabled people also supported the moves. They and their learning disabled members were liberated from the straight jacket of a dismal future to dare to hope that life could be fulfilling for them all.. Other families actively fought the moves and vociferously objected. A national, relative-led lobby - RESCARE- was formed, campaigning for the provision of congregate long term residential provision, and this organisation operated with other voluntary organisations actively supporting inclusive living. Some welfare agencies were able to adapt quickly to the changes in service delivery and others were not. Community based services required close collaboration of the major welfare agencies - health and social services - at top, senior and middle manager levels, as well as at the levels of contact staff. Budgets would have to be pooled, and ideally, as stated in the Model District Service, health and social services be delivered jointly. Some senior managers would have their power within their organisations reduced. Local politicians would have to be willing to share the setting and control of budgets as well as the shape of services provided: some wanted to, others did not. Community based staff, on the whole, supported the move, whereas a lot of hospital and hostel based staff did not, and some hospitals wanted to retain hospital provision. Policy makers and service managers supported the move, whereas hands on staff were sometimes unsupportive. Community based organisations, that had never had to think about incorporating learning disabled people, now had to find ways of including them in their activities. Leisure centres had to revise their schedules and consider physical access to their buildings and activities; youth services had look at their accessibility to learning disabled people; colleges had to undertake curricular developments to cater for people who might previously have moved from schools to hospitals; Many ordinary people had never met a learning disabled person, and stereotypes, which sometimes led to fear and apprehension abounded, fuelled often by local sensation-seeking media. Some local people and communities welcomed learning disabled people in their midst, and others did not. Community campaigns to keep people who 'should be in hospital' out of residential districts were mounted by local groups of people or individuals..

The complexity of the different stakeholders in the lives of learning disabled people, all of whom were in a position to exercise considerable power and influence over them, can be seen in Figure 1

Figure 1 about here

(It is interesting that this diagram, produced by the RHA excludes most generic community organisations, both formal and informal. This reflects the thinking at a regional level that the task was one of organisational change, not community development.)

Very few of these stakeholders were neutral about the changes.

Ranged along the complex battle lines were two sets of interests. Firstly there were those who supported, but were not always able to deliver both ordinary life futures for learning disabled people and for whom acceptance of some of the most vulnerable people in the land into local communities was a major goal. Then there were those who resisted, challenged and fought the changes with objections that ranged from the philosophical to the personal. Figure 2 illustrates the different communities to which learning disabled people belonged. Conflicts existed in all of them.

Figure 2 about here

It is amongst these conflicts that the Development Team worked, to strengthen alliances amongst those supporting (or potentially supporting) change, and those resisting or sabotaging change. Figure 3 outlines a model of service development functions.

Figure 3 about here

The work of the Team

Initially, the Team worked mainly with the primary welfare organisations to bring about principled change. Even this focus of the work was not simple. Welfare organisations operate in the midst of a web of different, often conflicting ideologies that at different points in time create a climate of uncertainty and turbulence. The last decade in Britain has seen particular ideologies gain a stranglehold on many different sectors of social life. The ideologies of the 'new right' (Levitas, 1986), which stress anti-egalitarian individualism and autonomy, and traditional family values (within which are enshrined patriarchal ideologies of work and of caring wherein men work as the major breadwinners, and women do the caring), have contributed to the strengthening of those ideologies which underpin self-help in contrast to state welfare (see, for example, Kagan and Lewis, 1994; Lewis, Kagan and Burton, 1995). At the same time greater centralised power has undermined the autonomy of locally determined welfare provision. However, there are apparent contradictions within these ideologies (Fawcett and Featherstone, 1994). Along with individualism and autonomy go the ideologies of consumerism - choice, consumer demand, and user participation in determining both client need and service responses to need. Along with the centralisation of power, goes a concern with quality, efficiency, effectiveness, and budgetary control. In the welfare field these ideologies enmesh the policy and legislation of 'Care in the Community'⁷ within which organisations serving people with learning disabilities

operated during this period. Furthermore, legislative changes led to major restructuring tasks for both health and social services. The internal market was introduced, and this caused major upheavals for both agencies (Robinson and Le Grand, 1994).

Strategies

Several different strategies were used by the Team (see Appendix 1). The ones I will highlight here are developing and strengthening alliances, enhancing knowledge and understanding and representation.

Developing and Strengthening Alliances

The strengthening and developing of alliances took a number of forms. The Team:

- mapped out and analysed existing interests and relationships; connected with key people in all districts throughout the Region (key people included learning disabled people, self-advocacy groups, parents or relatives, individual professionals at contact, or middle management levels, groups of professionals, interested politicians and so on. Different types of people were key in different districts);
- met with senior managers in the major health and welfare agencies and ensured that they endorsed the work of the team and were able to see that their agendas were being met⁸;
- co-ordinated developments in one part of the region with those in others, so that managers and staff did not struggle with the same problems unnecessarily

A new senior manager was appointed to take responsibility for all services to learning disabled people in one authority. This new manager had been involved in some of the Development Team activities in the past, and knew what was possible in other places. This authority then embarked upon a programme of change. The Development Team was invited to participate in this programme from the outset. People from other authorities who had faced similar changes in the different parts of the service (for example, day services, residential services, community supports, health services, etc.) were brought in by the Development Team and linked to key people in the authority. Over a two year period 'mentoring' relationships continued, and extended to parents linking with parents from other authorities, and learning disabled people linking with self advocacy groups in other authorities.

- linked middle managers in the key welfare agencies throughout the Region on a regular basis and ensured they had a focused agenda for collective action (for example, MHWG, 1988);
- undertook reviews and evaluations of services. By invitation, or sometimes at the Team's request, it visited services with a team of people drawn from around the region and from different agencies, and including learning disabled people or their family members and evaluated them. Internal feedback was given and reports prepared for wide circulation if all stakeholders agreed. Each review team was debriefed in terms of how they might take what they had learnt from the exercise back to their own agency or district and implement some of the new ideas they had met either in the review itself or in the discussion and distillation of the review by the Team for its feedback (for example, NWTDT, 1990b; 1991b; 1992b; 1993a);

A district (including a large town and two smaller ones, and several outlying villages) invited the Team in to review all of its health services. It did this because it wanted to be able to demonstrate the 'leading edge' nature of its provision. The Team got together a visiting team of people from other

areas, including a parent of a learning disabled adult. The visiting team identified a number of strengths of provision locally but also exposed a number of bad, sometimes abusive practice. The parent member of the team was adamant that some of the employees should be dismissed from the service. The Team worked hard to identify the best ways of feeding back its findings to the District, so that the likelihood of change was maximised. It presented its main findings and recommendations for change to the top and senior managers that had commissioned the work. The Team's report was received with great hostility and anger. The Chief Executive of the Health District shouted and banged the table, accusing the team of bad faith and a conspiracy to undermine *his* services. He refused to countenance any of the recommendations the Team made. He refused to make the report of the visit public and available for wide dissemination around the Region. Because of its networks and contacts, the Team had a good idea of who, within the District might be an ally for change. Despite a hostile senior management, the Team continued to work in supporting key personnel and family members in the district to identify goals for change, and to link them up with others in other districts who were confronting similar issues. Three years later, the same senior management invited the Team back to help them implement many of the recommendations of the original review.

- supported and contributed to a region-wide forum which brought together finance officers from each district got together with civil servants who administered welfare benefits in order to see how individual people's financial situation might be maximised once they were living in the community (e.g. NWDT, 1989);
- co-ordinated working groups of people from around the region in looking at specific aspects of service provision in order to produce good practice guidelines for wide circulation (e.g. community integration; towards a region wide training strategy) or to spread good practice

Several authorities had begun to experiment with recruiting ordinary families to accept a learning disabled person to live with them. The Development Team drew on the experiences gained in these authorities to try to spread interest around the Region. A series of regional workshops and visits were arranged so that those who had tried the arrangements could talk to those who were sceptical. One of the most powerful stories told during this process, was by one middle aged woman, who had had a number of learning disabled people living with her since her husband had died. She said "If only I had known that his sort of thing was possible, and these (learning disabled) people existed, I could have done so much more with my life". This was a powerful indictment of how well meaning welfare agencies deny ordinary people access to the lives of learning disabled people.

Increasing Knowledge and Understanding

In participating in the alliances outlined above, increased knowledge and understanding was gained by a large number of people in all the constituent districts in the region. A number of other, specific strategies to increase knowledge and understanding were developed. The Team:

- developed a series of publications with wide circulation around the Region. These included a regular newsletter of innovations, success stories, stories about the changed lives of learning disabled people and featuring people doing ordinary things with ordinary people; a series of research reports, providing information and material that people could use in their own strategies for change; a series of service reviews in which services, from single unit or entire districts would be evaluated and recommendations for change be made as well as the highlighting of good practice. The service reviews included some which focused on practice and outcomes for individual people which were outside the Model District Service pattern of living (NWDT, 1988a); a series of good practice guides, identifying specific features of good practice within and between services (Kagan, 1992a; NWDT, 1988c; NWRHA, 1992; 1993b; NWTD, 1990c,d; 1995a); series of

policy statements, drawing together principles and values underpinning the development of new service areas where gaps existed (NWRHA 1990c;1992; 1993a,b; 1995; NWTDT, 1993); short briefing reports which presented statistics of service innovations in new and accessible forms (briefings were produced on topics as diverse as, for example, networking in community building; ethnic minorities and learning disabilities; limitations of setting up a small business for people with learning disabilities; choking and major tranquillisers; financing supported housing; and rambling for all). As the major agencies funded the Team, wide circulation was achieved at no extra cost to individual services or districts. The Team attempted to include agencies hitherto excluded from some of the thinking about innovative practice as recipients of written material, including, for example, voluntary groups, parent led groups, housing agencies, schools and education agencies, colleges, leisure services and more informal community organisations.

- provided training workshops, in conjunction with a sister training team, also region-wide. These workshops offered basic values and principles training (e.g. Social Role Valorisation training) as well as leading edge skill and service development training (e.g. Personal Relationships and Sexuality; Interpersonal Skills; quality assessment). All these training workshops were attended by people from different agencies, at different levels, from throughout the region, as well as family members and learning disabled people themselves)
- worked with groups of staff to develop their skills for supporting people and helping them integrate more fully in local life;

A young man with a reputation for violent behaviour, was being brought back to his own neighbourhood from a residential school some 250 miles away. The staff unions of the facility in which he was to live were about to withdraw their co-operation, because of his bad reputation. Two of the Development Team members worked with the staff team to enable them to find ways of getting to know the young man prior to his move, and to identify, for themselves, an appropriate support service for him. This ended up looking quite different from the existing service, and the Team members supported them in arguing for their service with senior managers who did not want the service to change. Once the young man had moved, the Team members continued to support staff in thinking about how they might integrate him in the neighbourhood, and how they might try to bring more people who were not paid to be with him into his life. They continued to do this over a 3 year period, during which time the staff were unable to continue to support him at times, and he was removed to a more secure setting. The staff team were encouraged to make contact with others in other authorities who had managed to find ways of supporting similar people. Gradually the Team members were able to withdraw as staff developed their own networks of support. The young man is now living in his own home with staff support, and participates in lots of things, locally.

- provided training workshops for particular services with a focus on how the services may progress (workshops were commissioned on, for example, teambuilding; supervision of staff; working with people whose behaviour challenges services; quality assessment);

In one authority day services were experiencing a severe cut in budget. Coupled with this, staff had participated in some of the Regional training events and wanted to transform their services. A Development Team member was invited to work with the staff on service development in the context of contracting resources. She was able to help the service see that the future day time lives of learning disabled people did not depend only on the resources available to the day services. The local area also had a lot of resources to offer, and local people did too. She helped the team identify priorities for change and for community development, and was involved in a 5 year programme of change. Her role was to meet with staff, learning disabled people and their families, to review progress and identify further goals on a periodic basis. As staff changed and family-staff relationships changed, much of the

work was on team building and strategies to ensure that all the stakeholders were moving in the same direction. Learning disabled people living in this authority now do a far wider range of activities, not all of which are provided by the formal services. Many have jobs and take part in voluntary work.

- worked with parents, many of whom had never met other parents of learning disabled adult children before, to help them clarify their hopes and desires for their sons and daughters, or to find ways of ensuring their sons and daughters lived good quality lives out of the family home;
- worked with family members, often parents to help them find ways of actively participating in the planning and sometimes provision of supports for their sons and daughters (e.g. Kagan, 1993 a,b);

The Team was asked to help a district work towards a strategy for supporting people whose behaviour was a challenge to existing services. Initially, it was only the main health and welfare agencies involved. Each considered themselves to be the expert and thought that they should take the lead responsibility (and have the resources) for service development. The Team member worked to get these agencies to see that parents, supporting people whose behaviour was also challenging at home, should also be involved. She co-ordinated meetings with parents and worked with them to identify their concerns and to develop the confidence to relay these to top managers in the health and social service agencies. Through a series of meetings and workshops, she was able to get all the stakeholders, including families, as well as all levels of the health and welfare services to share their perspectives and ideas for change. Initially each mistrusted the others, and senior managers thought that policy development alone was all that was needed. By the end of the process (two years of Development Team involvement) the agencies and family members were able to work together on the development and implementation of a strategy to support people whose behaviour challenged services in ordinary life living. The parents had met with others in similar situations in other authorities and continued to meet as a support group for each other.

- helped individual family members and learning disabled people themselves bring together local people, friends and relations who cared about the future life of the learning disabled person, to help plan and sometimes provide for her or his future care (Pearpoint, 1990)
- provided courses for parents, family members and learning disabled people to learn about the social policies, services and possibilities in their lives (Gathercole and Elwell, 1996).

A Team member had discovered a course for parents and relatives of disabled people, run in the USA, and which sought to enable them to have as much access to knowledge and information about policies and practices of care for disabled people as any of the professionals. He encouraged some parents in the region to travel to the USA and find out about the course. He worked with the parents to adapt the course and run it in the North West. He moved to get some important voluntary organisations to support the course financially. The course was run for learning disabled people and their family members, many of whom have become more skilled and effective advocates and spokespersons for the rights of learning disabled people. There would have been nothing, in principle, to prevent each district mounting such a course for its residents. However, professionals and policy makers are reluctant to relinquish the power of information, so the Development Team did it for them.

Knowledge and information was cascaded throughout the Region from top managers to families and friends of learning disabled people. Despite attempts to demonstrate the importance of involving ordinary people, many of whom will never have met a learning disabled person in some of these activities (e.g. Kagan, 1992c; NWTDT, 1990d, 1991b) relatively little progress has been made, region-wide, in so doing.

Representation

Over the years the Team has been directly and indirectly involved in helping learning disabled people, their family and friends represent their best interests, and get the resources they need for the futures they need. Some people have become better able to represent themselves as a result of their greater knowledge, gained through participation in some of the above processes. In addition, Team members have:

- given advice, consultation and support to neighbours of people who were being exploited;

A Team member supported a neighbour of a learning disabled man protect his rights. She was contacted via someone who knew someone who knew her! The man had been living with his mother who recently had moved to be with her other son in Australia. She (and her other son) were planning to sell the house the learning disabled man lived in and take the assets to Australia. He was to become destitute and thereafter housed by the local authority. The neighbour managed to interest a local solicitor in his plight who got an injunction out on the sale of the house, which was then put in trust for the man. He was then able to continue to live in his home until he died.

- been directly involved in disputes between family members and service agencies, representing the interests of people who cannot speak for themselves (see for example, Kagan, Knowles and Burton, 1995);

One authority invited a Team member to participate in the planning of the future of a learning disabled man who was unable to speak for himself. She was asked to contribute his perspective to the planning process. In the planning, professionals involved in his life wanted him to remain in an ordinary, domestic scale house near his family and friends. His parents wanted him to move to a small institution (53 learning disabled people) outside the Region, 60 miles from his family and friends. The Team member, as advocate for the young man was able to describe his life now and what was good about it, and what might improve it, within the values and principles of Regional policy. The parents abducted their son from his home and took him to live with them, in unsuitable conditions. In the midst of objections from professionals, a sister and the Team member, the authorities took what they thought to be the course of least resistance and moved him to the institution. The Team member was able to challenge this decision on the basis of its inconsistency with Regional policy. She was also able to support the young man's sister in gaining legal assistance and in monitoring his situation at the institution. Periodically, the Team member was able to write reports, and support the sister in writing reports, highlighting the situation the young man was now in and its comparison with how he was living before. The senior management in health and social services, as well as at the institution received these reports with hostility. The Team member was able to muster support from senior managers elsewhere in the Region who were trying to adhere to Regional policy. She was able to use her network of contacts to alert other relevant professionals to the concerns surrounding his placement. She was able to help the sister compile a case highlighting the deterioration he had undergone. Two and a half years later a decision was made to bring him back to his own neighbourhood.

- stimulated Citizen advocacy (Breedlove, 1990) throughout the region, and there has been an increase in ordinary people campaigning on behalf of the learning disabled person;
- pioneered and closely evaluated a model of leisure advocacy which has spread to formal agencies (Kagan, 1982)
- challenged local services to deliver appropriate care, and to enable people to participate in local life

A housing worker who had met a member of the Development Team at an event designed to bring more awareness of the values and goals of inclusive living for learning disabled people to relevant community care agencies, contacted her with some concerns. A learning disabled woman was living

with her elderly mother in a sheltered housing scheme for elderly people. All those around her were elderly. What little support she had had been removed and the woman seemed to spend all her time in her night clothes wandering around the complex. The Development Team member was able to bring local agencies together to review the placement, drawing on regional policy principles and her negotiation and teambuilding skills. She was able to work with the agencies locally so that they were able to jointly identify appropriate provision and support, and were able to link the learning disabled women with more appropriate local projects so that she did not spend all her time with elderly people.

- pushed, through various mechanisms, for learning disabled people to be represented on policy making bodies, and for staff to develop the skills of enabling and facilitating learning disabled people to have a voice, and to spread examples of innovation (Kagan, 1997a). Self advocacy has grown and learning disabled people have made an impact on some services as well as gained in confidence (Skelton, 1997).

Conclusion

All of the changes that have taken place, have taken place within a particular ideological context that both helps and hinders development. These very contradictions within the ideological web present possibilities for change. Progress has been possible within and between organisations for people with learning disabilities as different hegemonic coalitions have formed, uniting the interests of different stakeholders in the futures of people with learning disabilities (Burton, 1989, 1994; Kagan and Lewis, 1994). Thus hospital managers who have to reduce their costs may ally with social workers who want to help people with learning disabilities realise their potential, and with family members who fear they will be asked to continue to care for adult sons and daughters with limited resources, and with self advocacy groups who are concerned that people with learning disabilities realise their full social rights.

One of the things that we can see, clearly, is that overturning decades of exclusion, in practice, as well as in principle, philosophy and legislation, is slow. Whilst in some ways, change has been rapid, in others it has not. The conflicts arising in the process of development, in all the different layers of the project, are not resolved immediately. When the ideological basis of living for a whole social sector is challenged, it takes time for new ideologies, principles and values to be encountered, considered and assimilated by all. It takes time for the skills and capacities of hitherto marginalised people, and of those supporting them for change, to be clarified and extended. It takes time for experiments in change to come up with results that will convince sceptics and would be saboteurs. And it takes resilience, and the capacity to keep the principles and goals for inclusion in sight, whilst being able to work in different ways with different stakeholders, and power conflicts, for a small resource like the North West Training and Development Team to be able to catalyse⁹, and keep the developments on course.

And yet, even when multi-layered community development has taken place, when we look in detail at the lives of individual people, we find them relatively isolated, and still excluded from local community life (Harrison, 1997; Kagan and Roberts, 1992; Walker, Ryan and Walker, 1993). We still encounter opposition by ordinary people to the aims of inclusive living, and we still meet families who wish for a sheltered, segregated environment for their sons and daughters. (We never meet learning disabled

people who would wish to return to physically isolated, congregate living with other disabled people.)

The next set of challenges to the Development Team and to all those who are contributing to and supporting the alliances for change, are connected to the opening up of local communities, and how to bring more ordinary people into the movement for change (Burton and Kagan, 1995; Kagan and Race, 1996). It is just the same strategies that will be needed in the future. Energy will need to be focused on identifying the strengths and capacities of ordinary people and of harnessing these in the alliances for change. Knowledge and information will need to be extended to people who have hitherto not been involved at all in the lives of learning disabled people. Moves will need to be made to encourage ordinary people to understand and represent the interests of learning disabled people, directly or indirectly in all walks of life. None of this is about needing to find extra resources. It is, however, about recognising the need to redirect change and development activities towards ordinary citizens, so that will be able to include, and be included in the lives of learning disabled people, and thus participate in more inclusive living for all.

Appendix I The Work of the North West Training and Development Team

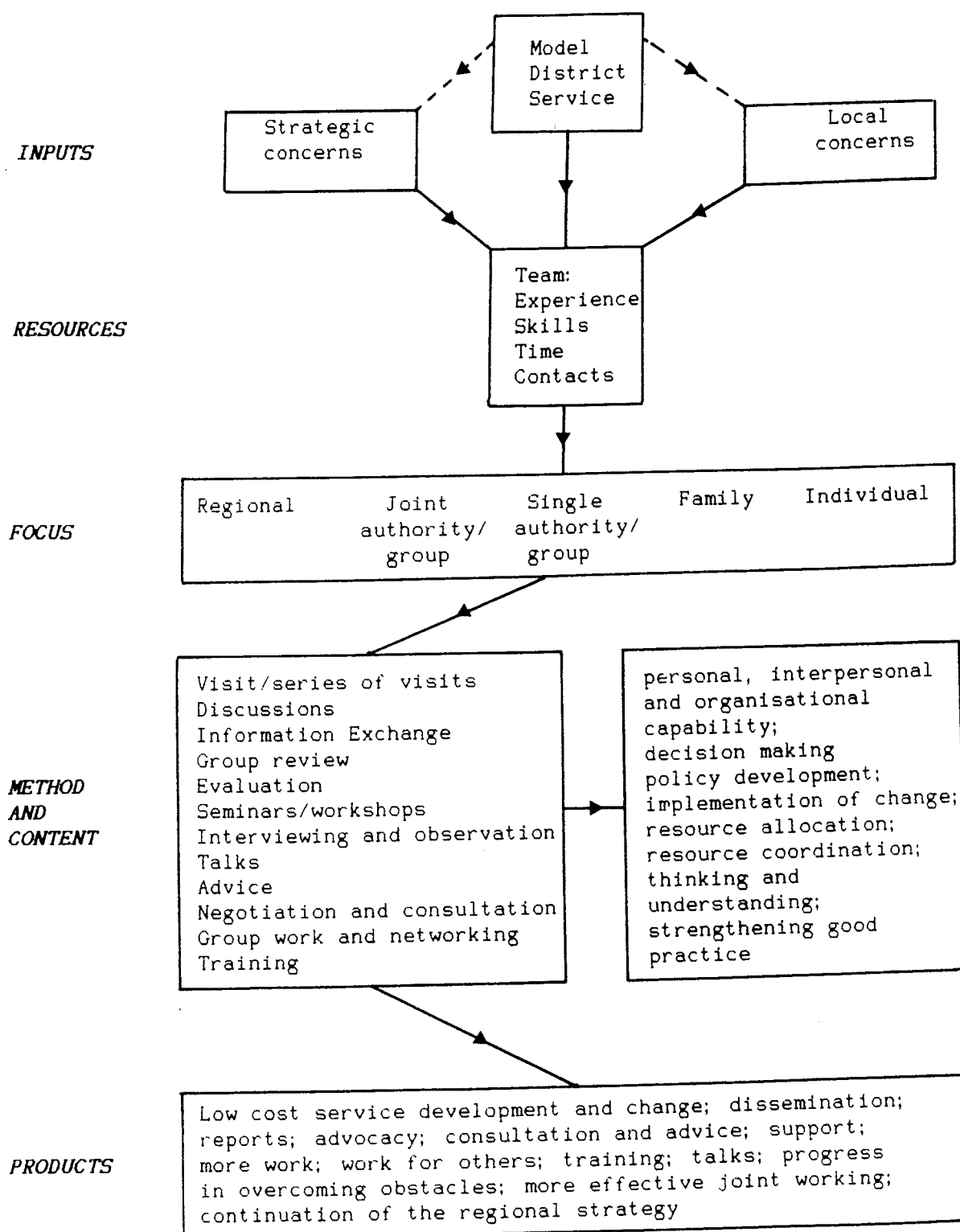


Figure 1 Organisational Relationships and Learning Disabled People

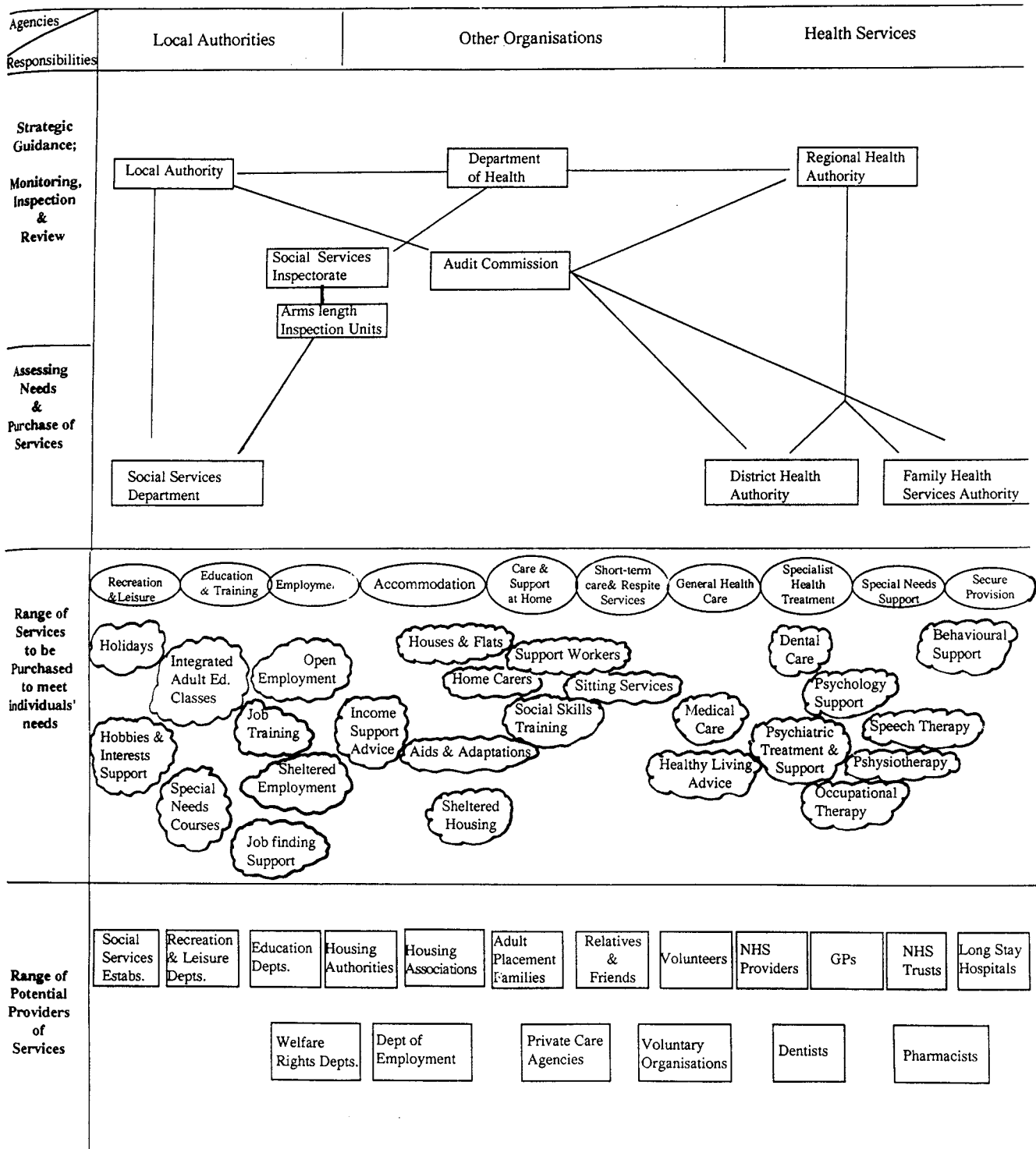
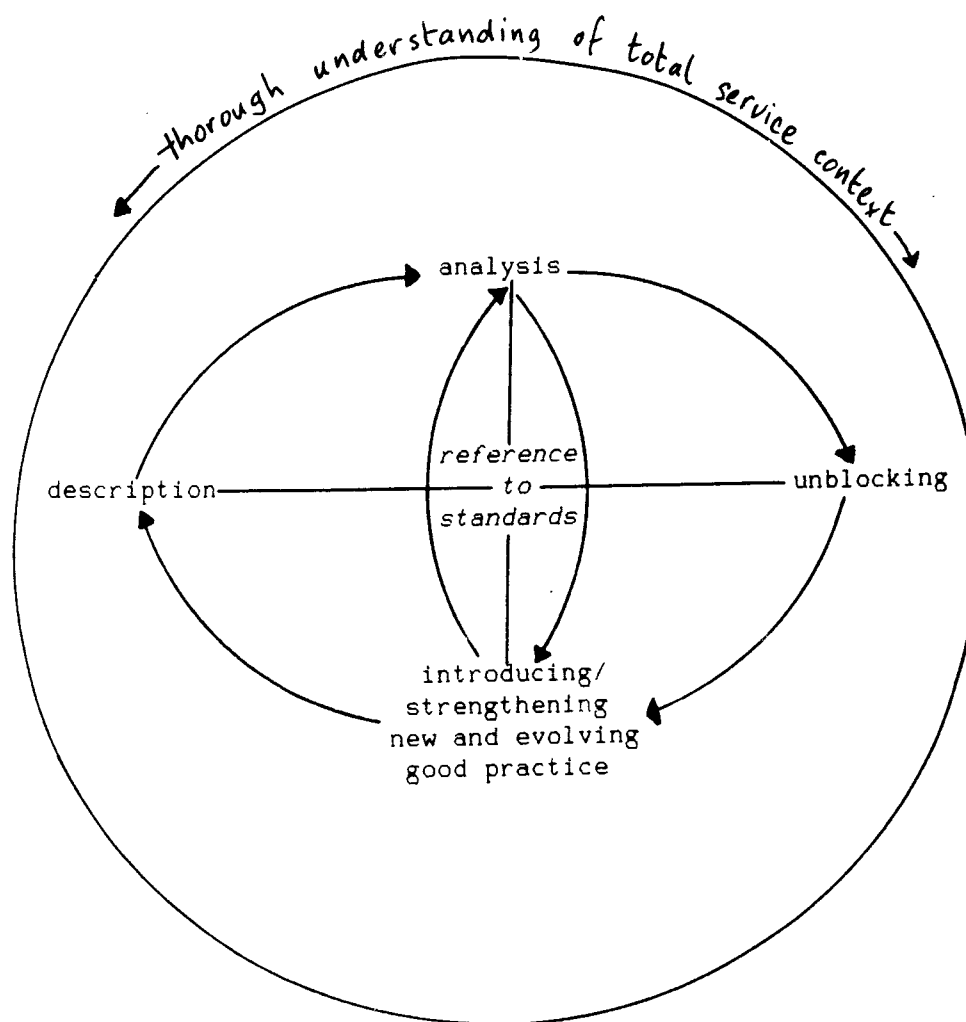


Figure 2 Communities of learning disabled people, indicating support and opposition to change (adapted from Burton and Kagan, 1995)

Helping change		Resisting change
<i>different layers of community</i>		
<i>Government community care reforms</i>	social systems at regional, national and international levels	<i>NHS Reforms (especially removal of NWRHA)</i>
<i>Regional policy</i>		<i>Budget cuts</i>
<i>MENCAP</i>	people, places, activities, organisations	<i>RESCARE</i>
<i>SCOPE</i>		<i>Private Care Sector</i>
<i>Reduction in public care sector</i>		<i>Unemployment</i>
<i>International trends</i>		
<i>development of work schemes, better residential services, colleges, support organisations</i>	people, places, activities, organisations in workplaces, localities and neighbourhoods	<i>local opposition campaigns (NIMBY - not in my back yard)</i>
<i>positive values</i>		<i>lack of contact, knowledge and understanding</i>
		<i>negative values</i>
<i>staff skills, values and commitment</i>	support staff and professionals in different direct services	<i>staff fear, threat, incapability</i>
<i>skills mix</i>		<i>professional rivalries</i>
<i>willingness to share power</i>		<i>unwillingness to relinquish power</i>
<i>families wish for change</i>	family, friends and relatives	<i>conservatism and fear of families</i>
<i>advocacy and belief in peoples rights and capabilities</i>		<i>uncertainty and belief in control</i>
<i>development of social networks</i>		<i>lack of friends</i>
<i>commitment to change and certainty that things could be better</i>	the learning disabled person	<i>uncertainty and lack of knowledge that things could be better</i>

Figure 3 A Model Of Development Team Functions (from NWDT, 1991)



¹ See for example, Room (1995) for discussion of the nature and measurement of the concept of 'social exclusion' in Europe

² Community is a particularly problematic concept when applied to learning disabled people, many of whom have lived socially isolated lives in the company of other disabled people, those who are paid to be with them or their families. Communities, here, refer more widely to the diversity of people living locally to learning disabled people, many of whom will never have met a learning disabled person before, and will know little about the services that support them, or the aims of inclusive living.

³ The North West has only been defined in this way in recent years. Up to 1994, the North West Training and Development Team worked only in Greater Manchester and Lancashire, with a brief to work in whatever ways possible towards better futures for learning disabled people and their families. The North Western Training and Development Team was established in 1987. It consists of an administrator and one full-time psychologist (funded by the Regional Health Authority on behalf of the 16 Health Purchasers), and three part time senior social work practitioners/managers/researchers - of which I was one, although I now work as an associate member with the Team - (funded by 17 Social Service Authorities). This, in itself is a unique resource in Britain. Nowhere else in the country do health authorities co-operate with each other in this way, or social service authorities co-operate in this way, or health and social services co-operate on this scale. Such collaboration is born of 15 years hard work developing and sustaining inter-organisational alliances (Kagan, 1997; Kagan and Lewis, 1994; Burton 1989). The team used to work to an agenda constructed internally, and was accountable to its sponsors via its Annual Reports (NWDT, 1988d; 1990a). These were distributed to, and subject to discussion with senior staff from social and health services around the Region. Since 1991 it has worked to an annual strategic work plan negotiated with the major stakeholders in its work (NWDT, 1992a; 1993b; 1994).

⁴ The Local Authority Circular (DoH 1992a) Social Care for Adults with Learning Disabilities (Mental Handicap) states *"there are probably around 120,000 adults in England with severe and profound learning disability, most of whom require considerable help in order to live, initially in their family homes and later in appropriate residential accommodation. This number may be growing as advances in treatment mean people with particular forms of disability have a greater life expectancy. In addition, there are probably about 30,000 children under 16...(and) there are many thousands of people with a mild or moderate degree of learning disability, whose needs for support vary widely, but must also be considered"* (Section 3)

⁵ The above circular goes on to say *"the Department (Of Health) estimates that currently about a quarter live in hospital and NHS community units, up to another quarter live in residential accommodation provided by local authority social services departments or the voluntary or private sectors.."* (Section 4)

⁶ Government strategy is outlined in legislation and associated guidance (DoH 1990; 1992a, b)...

⁷ The Model District Service pre-figured much of the Care in the Community legislation, but once the legislation was introduced the moves to implementing the model District Service were embedded within it (DoH, 1989)

⁸ Regular reports on the work of the Team were submitted to Senior Managers and politicians. The Team was supervised by the Director of Social Services and Director of Community Care at the Regional Health Authority taking the lead on the implementation of the Model District Service who were in a position to guide and endorse its work in fora which were hostile to it

⁹ The notion of 'catalyse' rather than, for example, 'create' change is in acknowledge of all the other parts of the coalition for change. The North West Training and Development Team could not work in isolation. This is an important part of the thinking about community development for social inclusion of learning disabled people - it will always take place in a context that is variously enabling or disabling.

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