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Report of the development of understanding of the *Family Based Intervention for Children with Cerebral Palsy and their Inclusion in the Community* project from the perspectives of occupational therapy and community psychology

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Kolkata, March 2002

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Introduction

As we are an occupational therapist and community social psychologist, we have incorporated our thinking about the *Family Based Intervention for Children with Cerebral Palsy and their Inclusion in the Community* project into a report that combines community psychology [see Kagan, C. and Burton, M. (2001) *Critical Community Psychology Praxis for the 21st Century* Manchester, IOD Research Group; Krishna, B., Chhetri, M.B. and Choudhury, S.P. (1998) *Learning Together: a manual for trainers on community based rehabilitation IICP, Calcutta*] and occupational therapy perspectives.

Through our discussion with the project team and with each other, we have found this a useful way to develop new thinking about the work of the project in relation to social change, and the use of a wide range of different sources of information that can contribute to this change.

The context of the Project

The project developed from the experiences of IICP in developing community based work with disabled children and their families living in rural areas of West Bengal (using a community based rehabilitation approach), and in the service gaps that have been revealed by families attending the IICP center in Kolkata. It was decided to explore ways in which community development approaches might be used to develop the provision of services to disabled children from economically disadvantaged families living in slum areas.

Collaboration with two UK partners who had worked on earlier collaborative projects led to funding from DFID via a Higher Education Link Project which sought to build the capacity of both families and community organizations to work with disabled children, via an action research process. A number of DFID objectives framed the project, including:

- Access to information and life skills and literacy,
- Efficient use of productive capacity
- Removal of gender discrimination
- Facilitation of a more positive self image amongst women

In order to address these objectives, a number of features were built into the project, including:

- making available both existing theoretical and practical information
- devising materials matched to the existing literacy skills of members of the community, especially women.
- utilizing the resources and strengths of the family, particularly mothers, to help the child with cerebral palsy and act as a catalyst for harnessing resources of the family and community
- developing teaching and training skills, and training community workers, using participatory methods,
- enabling family members to become more aware of their strengths, rights and potential
- working in ways that maximize the possibilities for inclusion of children with cerebral palsy and their families within the existing facilities available in the community
- integrating knowledge, awareness and support of disability within existing community development
- building systems and knowledge about awareness of, and support for disability in disadvantaged urban communities
- working in ways which may be replicated elsewhere, and may be sustainable.

IICP built its prior experience of particular NGOs in order to develop partners for the project.

During the time of our visit conflicts were occurring in Gujarat, with some related episodes elsewhere in the country. There were newspaper reports of redundancies from large corporations. There was some evidence of a 'modernisation' agenda being followed, with public amenities (for example filtered water in Kolkata) being charged to citizens. Although neo-liberalism has not got such a tight grip as elsewhere in the world, the signs of its incursion are evident [see for example Shiva, V. (2000) *Stolen Harvest: the hijacking of the global food supply* London, Zed Books].

The Disability Act and the Human Rights Commission act as progressive forces for disabled people, although the extent of their impacts on the lives of the poorest families is not yet known..

Community Psychological and Occupational Therapy perspectives on the project

Community psychology and occupational therapy offer some frameworks for self-aware social change, with an emphasis on value based, participatory work: one that is pragmatic and reflexive, whilst not wedded to any particular orthodoxy of method. Thus within a community psychological approach, different sources of information might be combined to develop an integrated picture of a complex change project. This project was conceived as an action research project, and as such, opened the possibility for learning at a number of different levels. An interim report of the project [IICP (2002) *Draft year 2 Report of family Based Intervention for Children with Cerebral Palsy and their Inclusion in the Community*] drew attention to the idea of prefigurative action research, which

"... emphasises the relationship between action research [... and practice...] and the creation of alternatives to the existing social order. This combined process of social reform and [...reflection...] enables learning about both the freedom of movement to create progressive social forms and about the constraints the present order imposes. It also creates disseminated 'images of possibility' for a different way of ordering social life." p.73

Kagan, C. and Burton, M. (2000) Prefigurative Action research: An alternative basis for critical psychology? Annual review of Critical Psychology

It is this prefigurative nature of the action research contained within the project that is one of its strengths .

Not only does a community psychology perspective include the process of action research, it also has a number of other features that can be applied to the project.

An Explicit Value Base

Community psychological perspectives have an explicit value base, one that is linked to an agenda of increased social justice [see Kagan, C. and Burton, M. (2001) *Critical Community Psychology Praxis for the 21st Century Manchester*, IOD Research Group)]. Social justice for disabled people and their families is closely linked to social inclusion in all walks of life, not just in a restricted range of life experiences. Such inclusion can not be achieved by disabled people and their families in isolation. The active assistance and collaboration of those professionals, community organisations, other community members, as well as Government policies and legislation are all important. These will often have to be fostered and nurtured, with explicit strategies for action.

This project has begun to develop an understanding of how social inclusion for disabled children in slum areas may be increased and has considered the lives of slum dwellers, and agency work, within a wider social context.

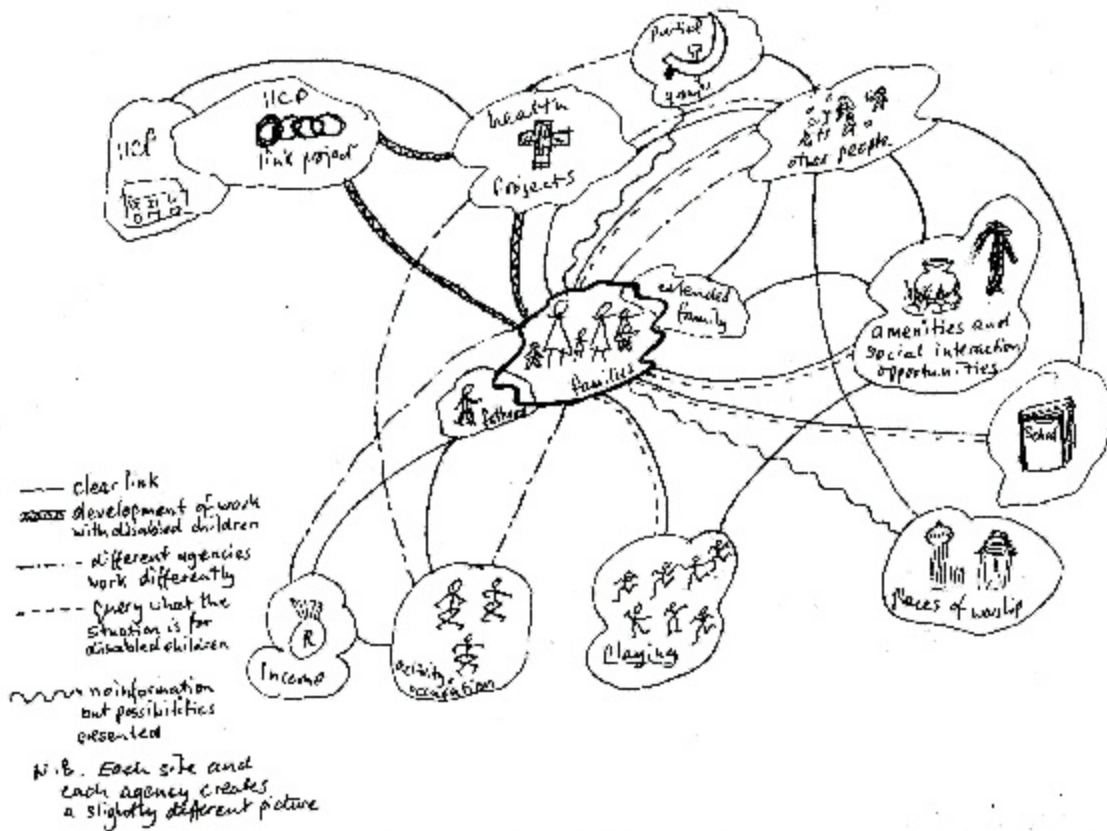
Ecological Metaphor

In community psychological practice efforts are made to look outside the individual for explanations of social experience and sometimes for solutions, whilst at the same time viewing people as agentic, purposeful beings who have the potential to influence and change their situations. The 'person-in-context' (where context is seen as being multi-level) is the unit of analysis and change, and this has become a guiding principle of both community psychology and occupational therapy. Pursuance of an ecological metaphor is closely linked to a whole systems analysis.

Whole Systems Perspectives

There is wide agreement in both community psychology and occupational therapy, that systems analyses of social change are required, both as a catalyst to understanding but also as a guide to action. Systems are not to be seen as static, concrete entities, but rather as social environments that can be both oppressive and supportive and that change over time. See figure 1 for our summary of the complex social system in which families in this project are embedded. Any particular part of a social system can be, at the same time, both oppressive and supportive. For example, families, health, education and welfare agencies, hospitals, neighbourhood agencies and institutions, all have the potential to provide support to enable disabled children to maintain identity, and secure material resources. However, they also have the potential for oppression. Thus, for example, whilst the families in this project have the potential to facilitate the inclusion of their disabled children into community life, they may also serve to restrict them through over-protectiveness, lack of expectation and hope and so on.

Figure 1: The system in which families in the project are embedded.



It is important to recognise the contradictions inherent in systems perspectives: whilst the project has begun to look at the positive aspects of changing aspects of the system, the project team may find it useful to develop its understanding of any unanticipated negative consequences for children and families as a result of the changes introduced.

The Necessity to be Interdisciplinary

Systems analyses allow us to work with different parts of the system, or with the interconnections between different parts of the system, or with the system as a whole. It is almost inevitable that in any complex social change project – and certainly in this one, that parties with different experiences and discipline backgrounds will become involved. The strengths of interdisciplinary work, particularly focussing on the interconnections of different agencies and interests – or different stakeholders – are particularly relevant to this project.

Not only is the IICP team inter-professional and interdisciplinary, but partner agencies with different remits and experiences have been involved.

People's Understanding

People's Understanding

The philosophy of occupational therapy emphasises that knowing about the ways in which people make sense of their physical and social worlds is necessary, if we are to work with them for change. This requires a certain degree of humility and can only be achieved by spending time with people and listening to their stories about their past, current circumstances and hopes for the future. It is only by hearing about people's lived experience, in the context of their past and future aspirations, that we will be able to begin to understand their consciousness, intentions, and behaviours. More than this, though, we need to understand our own position in relation to those with whom we are working.

This project has included ongoing reflection and openness to learning and change. IICP staff have explored their own starting points in terms of knowledge about life in urban slums, and have worked on ways of identifying the impact this may have had on the project. Partnership agency staff have opened themselves to new learning and have been able to use their previous experiences and knowledge to grow their understanding. Families, too have moved a great deal in terms of their expectations and aspirations, and have taken onboard new skills and techniques.

The project is well and truly grounded in the experiences of families. To date it has not been possible to include formally family members in community worker training, but they have clearly learnt from families in their own homes.

In line with both occupational therapy and community psychology, the project methods are immersed in the lived experiences of people who are marginalized and oppressed. The importance of this cannot be overemphasised, as

(professional and academic) knowledge is partial. It can only be indirect knowledge, informative and explanatory. It lacks that firm footing in raw reality that turns knowledge into a mobilising force capable of leading to action ... Moral and political responsibility as well as scientific rigour, demand that the academic (and professional) world turn its attention to people living in poverty, not in the first instance to teach, but to engage in a dialogue and to learn from it ... *(ATD Fourth World (1999) Introducing the Knowledge of the People Living in Poverty into an Academic Environment Paris, ATD Fourth World)*

It is through the combining of 'expert knowledge' with the people's 'popular knowledge' that progress can be made. The project also recognises that it is those nearest the children that will have the ideas and energies to ultimately make a difference. The creative and determining potential of family and community members is recognised and built upon. As Freire puts it:

"It is as transforming and creative beings that men, in their permanent relations with reality, produce not only material goods – tangible objects- but also social institutions, ideas and concepts. Through their continuing praxis, men simultaneously create history and become historical-social beings"

Freire, P. (1972) Pedagogy of the Oppressed Harmondsworth Penguin, p.7)

These elements of a community psychological perspective on the project are summarised in Table 1.

Table 1: How the project fits an occupational therapy and community psychological perspective

| Element | Community psychological Implications for the project |
|----------------------------|---|
| Explicit value base | Seek to develop participatory, sustainable and lasting change towards inclusion for disabled children |
| Ecological Metaphor | Look outside the individual for explanations of social experience and sometimes for solutions, whilst at the same time viewing people as agentic, purposeful beings |
| Whole Systems Perspectives | So long as it recognises the contradictions inherent in systems perspectives has the potential for enhancing the supportive features of some (elements) of the systems in the interests of the people, including disabled children. |
| Interdisciplinary | Seek interdisciplinary understanding and practice, and use this understanding as a guide to appropriate action for inclusion |
| People's Understanding | Work as near to the people as possible, and in participation with them in order to challenge the status quo and achieve social change. Provide opportunities for enhancing the creative, determining potential of people |

Intervention Strategies

Four major strategies of intervention (each of which could incorporate different methods) characterise this kind of community psychological and occupational therapy practice: (1) developing understanding; (2) creation of new forms of social relations (new social settings); (3) development of alliances; and (4) giving away knowledge. The two main strategies used in this project have been *developing understanding* and *development of alliances*, and these will be discussed in some detail below. All the strategies are summarised in Table 2.

Table 2: Strategies for intervention within the project

| Strategy for intervention | Project achievements |
|-------------------------------------|--|
| Developing understanding: education | The project has successfully introduced new knowledge and skills within families and have begun to develop and implement a training package for the community workers. They have demonstrated their openness to learning as a team, and are prepared to share their expertise. |
| Creation of new social settings | The project has helped the three NGOs to begin to move to being the kinds of organisations that are able to incorporate disability issues into their work. They have also begun to consider how IICP might incorporate community development into their own work. |
| Development of alliances | In addition to the alliances formed with the partner organisations and HE link partners, there are emerging possibilities to form alliances with other community based organisations that might lead to wider social change. |
| Giving away knowledge | The team's strategies throughout have been to pass over knowledge and skills to community workers, and they have incorporated the expertise of family members and community workers. |

Developing understanding

A key task of both occupational therapy and community psychology, and of the project, is an educational one. The project has collected a vast amount of assessment detail, but did not appear to have a coherent framework within which it could be organised. Without this it is difficult to describe succinctly, the child-in-context, and progress within the project.

In order to gain a holistic understanding of the child within the family and community, a frame of reference was designed. Mosey [Mosey, A.C (1986) *Psycho-social Components of Occupational Therapy* New York, Ravens Press] proposes that a frame of reference is a method of organising and framing knowledge so it can be used for planning action, and this seemed what would be helpful.

The team is exploring the use of a frame of reference, adapted from the Person-Environment-Performance framework [American Occupational Therapy Association (1994) cited in Case-Smith, J and Pratt, J. (1998) *Occupational Therapy for Children USA*, Butterworth-Heinemann]

This considers the individual as having three categories of performance:

- performance components - underlying skills;
- performance areas - activities of daily living;
- performance context - social, physical and cultural environment.

The individual is viewed as an open system influenced by their environment and therefore performance should not be isolated from its context [Cristiansen, C. and Baun, C. (eds) (1991) *Occupational Therapy: overcoming human performance deficits* Slack, NJ., Thorofare] (see Figure 2).

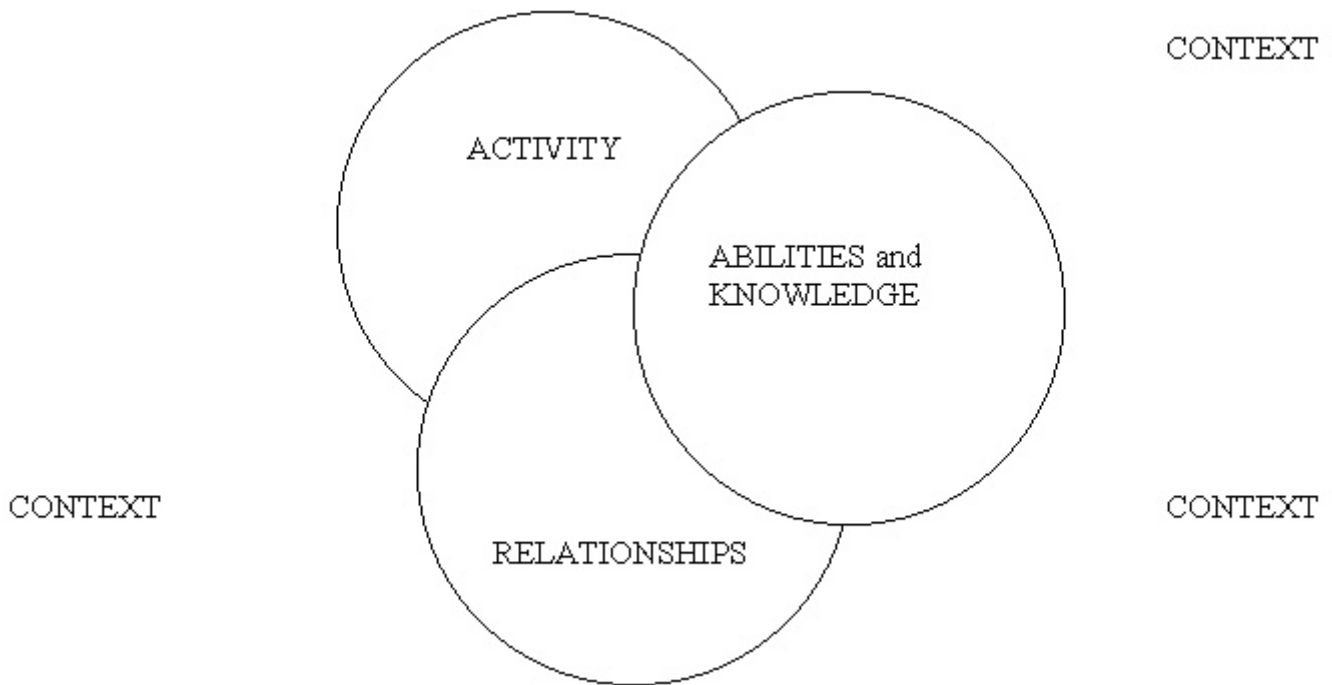
Each level of this project i.e. child, family, community could be viewed as three categories:

Activity -the valued activities that occupy daily routines

Abilities and knowledge – the underlying skills, knowledge, abilities necessary for daily living

Relationships – the influence of the relationships and acquaintances made within the social environment.

Figure 2: Frame of reference



These categories however should not be isolated from the wider context, which might include local, national and international priorities, values, beliefs and ideologies; legislation; and economic trends.

The different levels of child, family and community are interdependent. However, each level focuses on slightly different aspects of activity, ability and relationships. These are summarised below.

The child

Activity- considered the performance of valued childhood activities:

Self care – dressing, toileting, feeding etc.

Schoolwork - productive role - involvement in education, household chores etc.

Play and leisure – the participation in activities individually or in a group for pleasure .

Abilities and knowledge – considers the skills necessary to take part in valued childhood activities

Physical – gross ,fine motor and sensory skills etc.

Social – interaction, organisational etc.

Cognitive – attention, communication etc.

Emotional - feelings, hopes, dreams

Relationships – with care givers, parents , extended family, peers and others.

The Family -

Activity – valued activities that occupy the families' daily lives

Self care

Productive roles

leisure

Abilities and knowledge – considers the skills and knowledge necessary for every member of the family to participate

in normal life.

To include information about their children's past, present and future development, as well as the ability to access resources and practical skills.

Relationships – formed or acquaintances made with those around them e.g. family members neighbours, children, workers, others.

The Community

Activities- valued activities that those in the community may involve themselves with e.g. communal activities in the bustee, religious activity, economic activity.

Abilities and knowledge – to include knowledge of training resources available, health projects, work skills, education, other agencies such as IICP.

Relationships - Links formed with agencies, health workers and relationships made with local people beyond their bustee, such as religious leaders, and politicians.

Development of alliances and counter systems

A major strategy for social change, from a community psychological perspective is the development of alliances. In order to do this, there must be trust between different members of the different agencies or groups to be brought together. This project has achieved a great deal in developing trust and the interchange of ideas. One way of thinking about this is to see it in terms of developing social capital. A useful distinction can be made between 'bonding capital' and 'bridging capital'. Bonding capital refers to the relationships and activities, trust and co-operation that bring people closer together: bridging capital refers to ways in which people are helped to establish connections outside their neighbourhoods, or agencies, and that enable them to get ahead or work more effectively [see Kagan et al (2000) *Community activism, participation and social capital on a peripheral housing estate* European Community Psychology Conference, Bergen - available at <http://www.compsy.org.uk>].

Not only has the project successfully developed alliances, it has used its resources effectively by combining the expertise of different agencies, including IICP as well as the families, in order to produce change.

The complexity of the community system with which the project works, means that the different elements of the work of the project and the resources available, have to be focused carefully if any coherent community development is to be achieved that is of benefit to those living locally.. One way of thinking about the work is to see everything that is done as being at the interface of at least two different organisational eco-systems (or parts of them). The transition between two or more diverse ecological communities is known as the ecotone [see Odum, E.P. (1971) *Fundamentals of Ecology 3rd Edition* Philadelphia, Saunders Press; Mollison, B. (1991) *Introduction to Permaculture* Tyalgum, NSW, Tagari Pubs]. At such junctions, the variety and diversity of species and thus the productivity of the ecotone is usually greater than the sum of each of the adjoining communities. Not only do species from each community share the ecotone, some species are only found there. Furthermore, the junction between communities often acts as a kind of net or sieve for resources - they accumulate at the boundary.

The increased variety, resources and productivity of the ecotone is known as the 'edge' effect. Mollison highlights the importance of the 'edge' for sustainable development: the economies of at least two different environments can be combined and the natural benefits of each environment can be preserved. The same may be true of sustainable organisational development. By working at the 'edge', the combined resources of adjoining eco-systems can be used. Just as it is possible, through the design of sustainable systems of ecological development, to increase the relative contribution of the 'edge' to each adjoining community, so it is possible to create a larger edge effect in organisational development and thereby maximise its benefit to the organisational eco-system as a whole. This is, in effect what the project is attempting to do with some degree of success to date (see Appendix 1).

If we are successful in maximising the 'edge', it will be possible to maximise the energies and resources available to the community development process, and be energy efficient, whilst contributing to sustainable change. As the project hopefully extends, with such a small human resource facing such a large and complex community development task, it is essential that the work is carried out in sustainable and energy efficient ways.

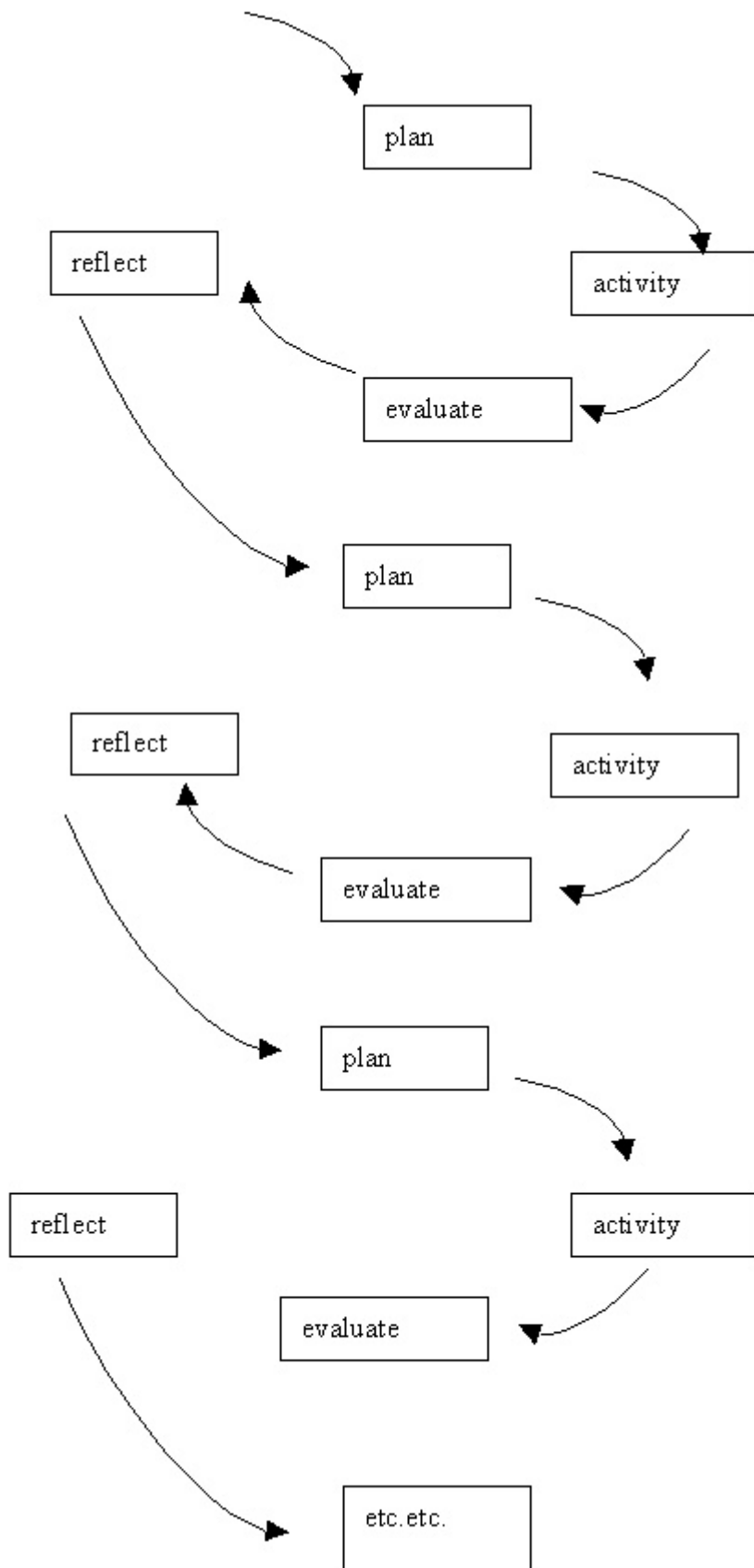
Not only do alliances increase strength for change, they can also lead to empowerment of vulnerable people [Burton, M

and Kagan, C (1996) *Rethinking Empowerment Shared action against powerlessness*. in I. Parker and R. Spears (eds) *Psychology and Society* London, Pluto Press] and also increase the likelihood that change will be sustainable.

The Project as action research

The project has successfully completed a number of action research cycles. A simple action research process consists of interconnecting spirals of *planning, doing, evaluating and reflecting*, leading to the next *planning, doing, evaluating, reflection, planning And so on*. (see figure 3)

Figure 3: A simple Action Research Process



The cycles already completed can be described as follows.

Cycle 1:

| | |
|----------|---|
| Plan | project |
| Activity | develop proposal and secure funding; make links with partner agencies |
| Reflect | First steps |
| | |

Cycle 2:

| | |
|----------|---|
| Plan | Initial site visits |
| Activity | Carry out site visits |
| Evaluate | The possibilities within each site and how best to work |
| Reflect | On learning |

Year One report

Cycle 3

| | |
|----------|--|
| Plan | Needs assessment – pilot with partners and parents |
| Activity | Carry out needs assessment with 17 families |
| Evaluate | collate information and summarise to get overall picture |
| Reflect | On learning and training requirements |

Cycle 4

| | |
|----------|--|
| Plan | First training workshops and family interventions |
| Activity | Carry out first training workshops and continue site visits, modeling interventions |
| Evaluate | From field workers, IP and partner agencies the barriers and solutions to project development in relation to training and work with families |
| Reflect | On implications for the development of the project and its implementation |

Year Two report

Cycle 5

| | |
|----------|--|
| Plan | Second training workshop and transfer of family based action |
| Activity | Carry out training workshop – become more bottom-up; continue site visits handing over interventions to families and field workers and encourage problem solving skills; develop training materials building on agency strengths |
| Evaluate | Through ability, activity and relationships, collect information about children, families, communities and agencies |
| Reflect | On what has been learnt about the possibilities for including disabled children in social life of the bustees and for developing the capacity of NGOs to work with disability issues |

Year Three report

Cycle 6

| | |
|------|---|
| Plan | Production of training materials and cascading process linked to the wider agency and community context. Plan for wide influence and sustainability |
| | etc |
| | etc |
| | etc |

As with many different examples of action research, the cycles are not independent from each other and overlap to some extent. It is clear, however, that the project is successfully operating along a process of action research, and one challenge for the future will be to consolidate the learning at different levels and of different kinds in order to inform the extension and sustainability of the project, but also future projects of IP.

Our reflections of our visit

We recognize within our stay here that the project has offered us the opportunity to gain insights into: West Bengal, life in the bustees, the valuable work of IICP, interagency working and the application of our own perspectives to the project in India. We have been able to reflect upon our practice and see possibilities for the absorption of new ideas into our own professional work – both practice and teaching. The major discussions we have engaged in have maximized the benefits of the three perspectives – that of IICP, occupational therapy and community psychology, and we think we have gained more from the visit because of the diversity of the perspectives.

We have both learnt a lot about different methods of facilitation of discussion, and about our own capacities to work constructively with people we do not know, and who come from different professional backgrounds.

When we reflect upon what we may have been able to contribute to the project, it seems as if we may have helped the project team think about how they might be able to integrate their understanding in terms of the processes which have characterized the project; and clarifying systems perspectives of the child, family and social change.

We have been humbled by the force of human spirit of the people we had the privilege to meet in the bustees, who were able to live with energy and optimism, keen to maximize opportunities, whilst living in impoverished material conditions. The willingness of IICP and NGO staff to learn from and engage with poor people has been inspiring.

Strengths of the project

Our perceptions of the major strengths of the project are summarized below.

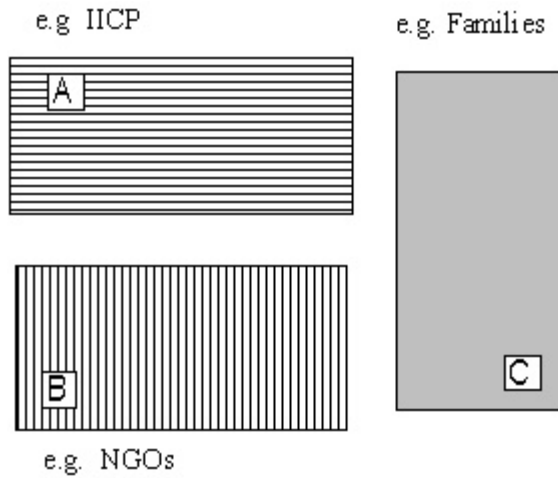
| Activity | Ability and knowledge | Relationships |
|---|---|---|
| Assessment Training of community workers Begun multiple stakeholder, process-outcome evaluation process Intervention with individual families Begun presenting findings | Rich material from assessments Possibilities of using training materials from partner agencies being pursued Knowledge of the lived experience of people living in the bustees Knowledge of disabled children and their families Further improved knowledge of, and use of reflection | Alliances with partner agencies Alliances with children and their families Possible links with wider organisations e.g. UNICEF Productive use of UK partners |

Appendix: Maximising 'Edge' Effects for Sustainable Development

Working within organisational boundaries:

Development and change targeted at each organisation separately.

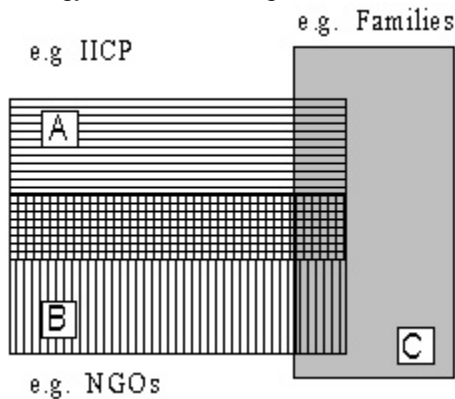
Energy inefficient and unlikely to lead to co-ordinated change in the common domain.



Maximising the 'edge':

Using natural resources - getting people from different organisations to work together and utilise the expertise of each.

Energy efficient and high likelihood of leading to sustainable and co-ordinated change.



Working at the organisational interface:

Attempts to bridge organisations.

Energy intensive: some likelihood of co-ordinated change, but effort is on the margins of each organisation's area of concern, so sustainability is questionable.

