ORIGINAL RESEARCH

A Low-intensity Approach for Early Intervention and Detection of Childhood Disability in Central Java: Long-term Findings and Implications for "Inclusive Development"

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ABSTRACT

Purpose: *This paper describes a qualitative follow-up study, conducted eight years after completion of a low-intensity early intervention and detection of childhood disability project in Central Java, Indonesia. The original project sought to increase the level of skills and engagement of existing community health volunteers, for the support of children with disabilities. This follow-up study explored long-term outcomes and implications for the inclusive development approach.*

Method: *Semi-structured interviews were conducted with 18 of the original volunteers. Interview notes were translated and thematically categorised.*

Results: *While the study was qualitative and descriptive, results indicate that despite the low intensity of the project, some early detection and prevention activities were still going on eight years later.*

Conclusions: *The study suggests that a low-intensity initiative such as this, which is closely aligned with the goals of a government department, may indeed achieve some ongoing change by extending the focus of the department towards disability-related concerns.*

Implications: *Implications are drawn for the emerging area of "inclusive development", which similarly seeks to promote change in mainstream services for the benefit of people with disabilities.*

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INTRODUCTION

In Indonesia, families of children with disabilities are more likely to live in poverty, have inadequate environmental access, live far from rehabilitation services, and lack basic information about disability, disability supports and educational services (Filmer, 2008; Suharto, 2006). Moreover, many children with disabilities and those with educational support needs are not adequately identified and do not obtain timely, early intervention support. This is particularly the case in rural areas, where 60% -70% of children with disabilities live (Filmer, 2008).

The traditional response to circumstances such as these in Indonesia, as elsewhere, has been to develop and implement Community Based Rehabilitation (CBR) projects which include a broad spectrum of activities. These may provide rehabilitation and inclusive education services, conduct rehabilitation training, provide information, support local community organisations, foster community attitude change, support CBR management, support referral processes, conduct training in disability prevention, provide vocational rehabilitation, and initiate income generation activities (Tjandrakusuma et al, 2002). While such initiatives are comprehensive and usually result in considerable outcomes for people with disabilities, families and communities, they are also difficult to sustain beyond the initial project. Such initiatives typically require considerable ongoing funding, high levels of infrastructure, substantial family and community engagement, skilled management, and significant support from government departments and staff (Tjandrakusuma et al, 2002).

On the other hand, in Indonesia as in similarly emerging economies, basic educational, health and social services are increasingly being provided to the population, and are extending beyond the major cities to district levels. In Indonesia, there is a relatively well-integrated and localised community health-care system (Shields & Hartati, 2003), in line with World Health Organisation objectives for primary health care (WHO, 1978). That is, each subdistrict has at least one community health-centre (called Puskesmas), which is linked to a number of community-level health stations (called Posyandu). These stations are staffed by nurses and midwives, and provide a range of services including family planning, immunisation, maternal and child health-care and preventive services. Integral to this, each Posyandu includes about five women volunteers or cadres working within their village (UNESCO, 2000).

Unfortunately, historically most Posyandu have not provided specific services for children with disabilities, developmental delay or special education needs. This has posed a challenge for CBR services in Indonesia; namely, "How can such agencies complement their traditional CBR services with efforts to increase the relevance of these extensive community health services to people with disabilities?" While not conceptualised as such in the planning of this project, this recognition of the need to foster change in existing health services so as to promote the inclusion of people with disabilities, partly corresponds with the emerging "inclusive development" approach. This emerging approach which is consistent with the United Nations Convention on the Rights of Persons with Disabilities (UN, 2007), and a hallmark of the new CBR Guidelines (WHO, UNESCO, ILO, & IDDC, 2010), is a multifaceted process rather than a specific method, which seeks to promote inclusion, diversity, and social change (Stubbs, 2009). In part it involves a shift away from stand-alone CBR projects towards promoting change in existing generic government and non-government development services. The model adopted by the Community Based Rehabilitation Development and Training Centre (CBR-DTC) in Solo, Central Java, sought to orient primary health-care services to the needs of children with disabilities, through training and supporting existing community health volunteers (Lysack & Krefting, 1993).

The Low-intensity Model for Early Intervention in Central Java

In 2002 the CBR-DTC, funded by the Jakarta Japan Club, implemented a strategy which sought to maximise the existing Posyandu and community health resources for the benefit of children with disabilities, children with special education needs and their families. The model was extensive rather than intensive, and it was envisaged that it would be self-sustaining (Lysack & Krefting, 1993), making a small contribution towards mainstreaming disability issues into existing health work, building collaboration and networking across sectors, and supporting universal primary education.

The project provided:

- Activities in each village, to promote general community awareness of disability and basic information on disability prevention.
- Targeted training for Integrated Health Post volunteers, village midwives, and subdistrict community health staff, for detecting disability and early intervention.

- Resource development (early detection and intervention manuals, relevant posters, educational toys, and disability aids and equipment where required).
- Implementation of three levels of assessment (namely: screening for all children, simple assessment if indicated, and formal assessment and referral of identified children to the community health doctor or therapist).
- Training and support for families of children with disabilities (basic community rehabilitation practices and processes).

From inception, this project was deliberately of low-intensity and brief duration, running from 2001 – 2002, focusing on four major villages in three districts in Central Java Province. The four villages were selected on the basis of discussions with local government, District Health Offices and Community Health Centres, acknowledging need, incidence of disability and existing community participation. Across these four villages (with a combined population of approximately 30,000, including 8,250 children), there were totally 178 volunteers linked with 40 Integrated Health Posts (Posyandu). To the greatest extent possible, training and activities provided by the CBR-DTC incorporated the volunteers and were integrated with their work.

In the first six months of the project, the main activities and training noted above were actively initiated and led by CBR-DTC staff, with village-level staff observing. In the following six months, to promote sustainability, CBR-DTC staff provided a support and back-up role, assisting volunteers, family members and community health staff to implement the training and intervention activities themselves. In the second year, the CBR-DTC staff role reverted to providing monitoring and consultation for volunteers, and the Centre fulfilled a community resource function.

Evaluation of the Project

On completion of the two-year project, the project evaluation (CBR-DTC, 2003) conducted in 2002/3 noted that:

- The project was appropriately targeted towards Integrated Health Post volunteers, recognising that these women were well integrated into the village and linked to the community health infrastructure, that they were credible contacts and effective agents of change.
- Integrating the disability and educational focus with the existing community health infrastructure was mostly effective.

- In some cases the medically-oriented nature of "upstream" services (community health centres and hospitals) was not conducive to the social, disability and educational needs of families and children. However, the substantial increase in referrals, the engagement of families, and the focus on disability at village level were constructive changes.

The aim of the current follow-up study was to explore long-term outcomes of the project from the perspective of volunteers who had been associated with it over the past eight years, and to consider implications of this low-intensity approach for the model of inclusive development currently being proposed (WHO, UNESCO, ILO, & IDDC, 2010).

METHOD

Eight-year Follow-up of the Project

In order to gain some anecdotal indication of the long-term impact of this low-intensity, short-term integrated project, follow-up interviews were conducted in 2010, with volunteer representatives from 18 of the 40 Integrated Health Posts involved in the initial project. Interviewees were selected on the basis of availability, with sampling from each of the target villages.

This follow-up study focused on staff and volunteers of the CBR-DTC project. The focus was organisational rather than pure research, and did not involve direct contact with people with disabilities or their family members. Consequently no ethics review was sought.

Village name	No. of Posyandu in the village	Total no. of Posyandu volunteers	Number of volunteers interviewed
Tembarak	3	16	3
Menggoro	10	28	5
Triyagan	6	27	5
Kutowinangun	21	107	5
Total	**40**	**178**	**18**

These interviews were conducted in the Bahasa Indonesia language, in the respective villages of the 18 volunteers. Two occupational therapists who had been involved in the original CBR-DTC project, conducted semi-structured

interviews (see Appendix 1) with one asking questions and the other recording responses in writing. Responses were subsequently translated into English. Translated interview notes were categorised according to question number and common themes by the first author. These were then summarised to identify common activities, outcomes and challenges.

RESULTS

Focus of the Project

When asked whether they remembered the project, all the interviewees said "yes". Despite five noting that they remembered it "only a little", 17 of the 18 interviewees recalled the emphasis on detection of childhood disability and early intervention.

When interviewees were asked about outcomes of the project, all 17 of those who recalled the project, noted the detection of childhood disability in their villages as a main outcome. Most interviewees also mentioned their own enhanced knowledge and understanding of disability, and working with children with disabilities and their families as a short-term benefit.

Long-term Outcomes

In response to the question about longer-term outcomes of the project, the majority of the volunteers described their own increased knowledge about disability and early detection. For example,

> *'I do not know if this is a long- term outcome or not, but for myself I feel I now know better about detecting disabilities among children under five, that I did not know before' (iv5).*

In addition to this, almost half of the interviewees described interesting flow-on effects of the project. They noted that some of the barriers to disability services had diminished, and that childhood disability had become more accepted:

At the organisational level,

> *'Before the project, (the village health centres) just paid attention to (non-disabled) children, but when the CBR Centre came to our village and gave training on detection of disability in children, the activities of the village health centres also included children with disabilities or developmental delay' (iv18).*

At the volunteer level, facilitating their work,

> *'Now we can visit parents who have children with (disabilities or developmental delay)' (iv2).*

At the family level,

> *'The awareness of parents towards children health increased. Many parents now bring their children to Posyandu regularly to consult their children growth and development some problems related to their children' (iv7).*

Maintenance of Project Activities

All interviewees stated that they carried on with the activities after cessation of the project, using the resources provided. Some said they no longer practised early detection and screening in a formal or separate way. For example,

> *'Yes. We still do early detection and intervention but not in the everyday routine. We just use the manual/ book from the CBR Centre, Solo, when we observe and find children with some problems' (iv8).*

For these interviewees, it had become more integrated into their general health-related work.

Interviewees did not describe any instances in which the disability-related focus initiated by the project had diversified or grown over the eight years. Likewise, it appeared that volunteers had not been able to expand activities relating to early intervention and childhood special education. It appeared that in many cases, the disability-related activities of the Integrated Health Post had continued largely as implemented by the project, or had been overshadowed by the more traditional health and nutritional functions of the Integrated Health Posts (which are quite consistent with the early-detection focus of the project). Some mentioned that the resources and information provided by the project had been broken or lost.

While all of the interviewees acknowledged local government support for the Integrated Health Posts (in the form of a small amount of funding), it appeared that this was still solely allocated to maternal and child health and nutrition concerns. Likewise, support and training from the Community Health Centres to the Integrated Health Posts and volunteers had continued as before the project, but very little was related to disability and special education issues.

Challenges

When asked about the challenges this work faced, the volunteers raised a number of important issues, which echoed the findings of a similar larger study conducted in nearby villages, nearly twenty years earlier (Lysack & Krefting, 1993). As in the Lysack and Krefting study, most volunteers described time constraints as a major challenge in their work,

> *'Most Posyandu Cadres are women. Sometimes we struggle to manage our time, we must do our domestic jobs for our families, and any of us must do their own job and beside that we must do our job health volunteer work' (iv4).*

Many felt that their limited education was an obstacle in understanding the issues involved in disability and early intervention, and as a result lacked confidence in doing their work.

> *'Problems related to children are complex. I just have low level of education, just graduated from elementary school. That is challenge for me' (iv8).*

Some also described the lack of acceptance of this particular work by family members, and the shame felt by some families, as ongoing challenges.

> *'To discuss about the children condition with parent is not easy. Sometimes parents are angry and misunderstanding, particularly parents who have children with developmental delay or disabilities' (iv1).*

Finally, when asked about how the project could have assisted them better, all the interviewees stated clearly that there was a need for more training and support. Despite strong indicators that volunteers had, to some extent, continued with their activities in detecting and assisting children with disabilities over the intervening eight years, interviewees consistently expressed disappointment that the project had ceased.

CONCLUSION

In conclusion, it would appear from our simple qualitative follow-up that this small, short-term project led to a degree of awareness and ongoing activity related to childhood disability issues, within the health service. Indications are that part of the success of the project was due to its connection with the existing health infrastructure. If it had not been linked to the government-supported primary health-care structure, it is questionable whether it would have had an impact eight years after completion.

As may be expected, the residual disability focus had largely been incorporated into the daily health-related work of the community volunteers. Such integration of disability work into mainstream service delivery would appear to be a positive outcome, and quite consistent with the goal of inclusive development. Despite their having expressed feelings of inadequacy, the training and use of unskilled volunteers who were already working within the community health service, appeared appropriate within this structure.

As implied in an earlier study on a related project (Lysack & Krefting, 1993), the low-impact extensive nature of the project, using simple skills training across four days, was an attempt to do "the best they can in a country without adequate financial and professional resources for rehabilitation services" (p.135). In reality though, a number of small-scale impacts, such as the volunteers' ongoing awareness of some childhood disability issues, and a degree of community responsiveness, were noted in our qualitative follow-up study eight years after completion of the project.

Despite the success of the project at grass-roots level, it appears to have lacked a higher-up systemic and structural focus. It focused on the volunteers, not the "upstream" community health staff, centres and structures. Possibly as a consequence, no significant changes in systems were noted in this study. It may be speculated that had the project equipped and trained the Community Health Centre staff and management as well, these higher-level workers may have integrated aspects of the disability work into their roles, or at least supported the activities in the same way that the volunteers did.

Limitations

The current small follow-up study has substantial limitations, and is intended to be used to provide some indications rather than a definitive conclusion about the original project. The authors sought to obtain a sense of how the focus of this work had continued, so interviews with the key staff members were used. A more comprehensive and inclusive study would have featured the perspectives of children with disabilities, their parents and families, but given the eight year follow-up period, this was beyond the resources of this study. Likewise, for a more comprehensive understanding of the long-term impacts of the project, interviews with teachers and managers of health and education departments would be required. Further, a more balanced study would also include substantial focus on quantitative measures of activity, outcomes and impacts for individual children, families and agencies.

Implications: Inclusive Development

Finally, as noted above, this small study also provides some insights of relevance to the current shift in which CBR is increasingly adopting the methods and terminology of inclusive development (WHO, UNESCO, ILO, & IDDC, 2010). This model, which seeks to promote inclusion, diversity, and social change (Stubbs, 2009), by fostering disability-relevance of other services, is not only consistent with the CBR model practised in many settings, but also reflects a shift from stand-alone CBR projects to mainstreaming disability issues into existing initiatives in other sectors. Inclusive development (like comprehensive CBR) seeks to build skills, awareness, collaboration and networking across sectors, to achieve broad goals such as inclusive health services, universal primary education and more accessible environments. In this CBR-DTC project, it would appear that a degree of collaboration and networking resulted in small-scale sustainable change in local health post practices, incorporating greater responsiveness of the community health sector towards early detection of childhood disability.

Understandably, there were no indications that this approach resulted in broader changes (such as poverty alleviation, human rights, greater consultation, improved access or social change) to which the inclusive development agenda aspires. This is largely due to the scale of the initial project and a function of the participants, questions and methods of this follow-up. However, this study suggests that making one small aspect of a health initiative more disability-focused is possible, and can even be enduring in a closely aligned setting such as child health. From this example, it would appear that the deliberate implementation of disability inclusive development will require not just practical downstream community-level actions, but also clear upstream efforts such as engaging management at all levels, fostering funding commitments and involving policy-makers. The clear need at this point is to conduct sound, value-based, participatory research on the process and outcomes of inclusive development implemented across multiple sectors.

In the interim, this study provides a concrete suggestion for an early step in such a research agenda. If CBR managers and policy-makers wish to seriously consider inclusive development, a good first step would be to identify instances in which aspects of these approaches have previously been employed in CBR settings, and qualitatively and quantitatively explore the effects of those initiatives, with particular attention to the perspectives of people with disabilities and their families. If properly researched, current and historical examples of attempts to orient existing services to meet the needs of people with disabilities in developing

countries and elsewhere, may provide us with suggestions of strategies, and evidence of outcomes of this approach for people with disabilities, families, communities, relevant agencies and government departments.

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Appendix 1. Semi-structured interview questions

Community Based Rehabilitation Development and Training Center (CBR-DTC) Solo, Central Java, Indonesia

INTERVIEW - POSYANDU CADRES
"EARLY DETECTION AND INTERVENTION PROJECT"

INTERVIEW QUESTIONS:

Thank you for agreeing to answer some questions about the CBR-DTC project, which was implemented from 2002 to 2003. We want to find out about the long-term effects (if any) of the project, and to hear what you think about it.

1. Do you remember the project and the support provided by CBR-DTC as part of the project? What do you think was the main outcome of the project at that time?
2. What do you think was the main long-term outcome of the project after it ended?
3. Does your Posyandu still do early detection/intervention? What kind of activities have you done recently, related to early detection and intervention for children under five?
4. What other kind of activities (serving children under five - or people with disabilities - or others) have been done by your Posyandu recently?
5. How did the project help your Posyandu? What skills or new things did you learn?
6. How many cadres are active now in serving your Posyandu?
7. Does the local village government still support your Posyandu? What kind of support?
8. Does Puskesmas still support your Posyandu? What kind of support?
9. In your opinion what are the challenges for your Posyandu to sustain services of early detection and intervention?
10. How could the CBR-DTC project have served you better?

Thank you for your time and comments.