

Rehabilitation of Afghans with Disabilities Community Based Rehabilitation programme (CBR) impact evaluation study protocol

1. Background for the study

1.1 Disability in Afghanistan: Growing interest and available information

In Afghanistan, until the National Disability Survey in Afghanistan (NDSA) (Trani and Bakhshi 2006), there was very little available knowledge about disability. Researchers, policy makers, organisations of persons with disabilities (DPOs) as well as persons with disability themselves agreed that there was a need for a scientific basis and valid conceptual framework in establishing disability statistics in the country. Carrying a survey on disability presented a particularly complex measurement. The NDSA was a first attempt to respond to the need for some evidence-based knowledge.

Assessing, or measuring disability is often a perilous exercise because of the difficulty to choose among alternative paradigms and to operationalize it into a survey instrument. The various models, theories and definitions propose various views of the phenomenon, ranging from a medical to a social approach. One major consequence of plurality of approaches has been a scarcity of work done in low-income countries and the lack of comparable data. Over the last decade however there have been major steps taken to reconcile the various views by looking at the disabling condition, or the interplay between the individual situation and the collective resources (and limitations) that may make an individual impairment a social disability. Two such frameworks that we referred to in the National Disability Survey in Afghanistan were the International Classification of Functioning, Disability and Health (ICF) defined by the World Health Organization (WHO 2001), and the Capabilities Approach that has been elaborated by Amartya Sen (Sen 1999). Efforts have been undertaken to improve and standardize the measurement of disability in population-based surveys based on the ICF (Loeb, Eide et al. 2008, Vanleit 2008). The use of the Capabilities Approach was rather innovative. We then shifted the focus towards looking at the individual within a context, a community and society as a whole.

To go beyond the description of the situation of the needs of persons with disabilities in Afghanistan, the RADIE study envisioned to explore what effort was currently being made to provide services, but also to include them in their community. The Community Based Rehabilitation programme implemented by Swedish Committee for Afghanistan (SCA) is the most important programme addressing specifically the identified needs of persons with disabilities and promoting their social inclusion and participation. We argue that providing a well-defined impact evaluation tool, tailored to the needs of the staff, easy of use and providing regular feedback for better monitoring the work of the CBR team will be of value to better fulfil the objectives of the programme.

1.2. CBR in Afghanistan

RAD is a CBR programme for persons with disabilities initiated by UNOPS in 1991 and handed over to SCA in 2004. This CBR approach aims at improving the lives and rights of people with disabilities and their communities and covers 13 provinces of Afghanistan. The programme is currently implemented in 43 districts with over 500 national staff, 4 expatriate advisory staff, 102 (36 female)

self help groups, 878 (341 female) community volunteers and 116 (35 female) community based support committees (CBRCs). RAD's regional project offices are based in Taloqan, Mazar-e-Sharif, Ghazni and Jalalabad and are responsible for daily running of the programme. In Kabul there is a Technical Support Unit at SCA's Kabul Management Office, which provides technical support for the programme as well as advocacy on a national level with government and other stakeholders. RAD is the largest CBR programme in Afghanistan, whose components include education and information about CBR and disability, employment support and vocational training, special and inclusive education, physiotherapy and orthopaedic services. The programme provides services primarily to disabled children, women and men. The physiotherapy component targets physically disabled people, whereas people with mental, visual and hearing impairments are covered by the special and inclusive education component. Physiotherapy services are further offered to patients with back pain, temporal and non-permanent injuries or problems that require physiotherapy. A continuing challenge is to make services available in remote areas, which will be able to satisfy the needs of persons with acute and permanent impairments.

1.3 A lack of available knowledge about Community Based Rehabilitation Programmes impact

A wide variety of very different and complementary approaches are taken in developing countries, such as Afghanistan, to adequately respond to the needs of persons with disabilities. Community Based Rehabilitation programmes are considered fundamental for improving the wellbeing of persons with disabilities, and for fostering their participation in the community and society at large (Cornielje 2009). The overall aim of CBR is to promote social inclusion of people with disabilities, enabling them to have the same opportunities as other members of society (WHO, ILO et al. 2010).

CBR programmes are also considered, in theory, to be the most cost effective approach to improving the wellbeing of persons with disabilities, in comparison with care in hospitals or rehabilitation centres (Mitchell, Zhou et al. 1993, Mitchell 1999). The original CBR strategy was to promote the use of effective, locally-developed technologies to prevent disability, and transfer knowledge and skills about disability and rehabilitation to persons with disabilities, their families and the community at large (World Health Organization 1976). However, more than three decades later, there is little literature providing evaluations of the impact of CBR programmes on the well-being of persons with disabilities (Biggeri, Deepak et al. 2012). This can partially be explained by a tendency to concentrate resources on the implementation of CBR rather than on research and evaluation about it. Within the CBR literature, which does exist, there are many identified gaps that pertain to the substantive issues the present research seeks to address. Firstly, there are still no universally agreed criteria for the evaluation of CBR programmes (Finkenflügel, Cornielje et al. 2008). Secondly, there is very little research available on the effective participation of persons with disabilities, families and communities in CBR. There is therefore little evidence to address the criticism that many CBR programmes are managed using a "top-down" approach, and do not effectively engage with persons with disabilities or their organisations. Sharma (2007) carried out an evaluation of 22 CBR programmes in 14 countries and found that only six measured community participation outcomes (Sharma 2007). Of those 6, only 3 included a quantitative measurement of community participation. Most of the existing research on CBR focuses on accessibility, importance of the programme, identification of needs and specific outcome. A few recent studies have added some knowledge but none are following a cohort of participants and controls through multiple waves of interviews (Mauro, Biggeri et al. 2015). To appraise a CBR programme, evaluation of community involvement, together with an assessment of the coverage of needs of persons with disabilities (in terms of service delivery, technology transfer) and economic and social inclusion, is essential.

1. 4 Importance of impact evaluation using mixed methods

- Providing reliable feedback to donors on the effectiveness of development program has become a pressing issue for NGOs.
- Measuring the extent to which the RAD CBR program has brought positive changes in the well-being of participants is important for the quality of life of participants, but also for the staff involved as it will show how meaningful their work is, and for the wider understanding of the relevance of CBR.

Impact evaluation is increasingly recognised as it brings new knowledge, it responds to a need for accountability and it gives insight into possible improvement of programmes (Wynn, Dutta et al., 2005). There is much debate about what is the best method to obtain reliable knowledge. Some authors argue that quantitative methods, particularly randomised control experiment constitute the “gold standard” for evaluating the effectiveness of development program (Cook et al., 2002). Critics argue that there is a difficulty to explain the change observed when the outcome is not a simple objective indicator: it is quite straightforward to identify an impact on a rate of employment after an intervention providing employment support, but it is more difficult to explain an improvement in subjective wellbeing when the intervention provides community sensitisation and disability advocacy. Randomised control trials can also be difficult to implement for ethical, political, financial or practical reasons. Other scholars emphasise the use of qualitative and participatory methods to carry out an evaluation (Lay and Papadopoulos, 2007). Yet, critics consider this approach cannot disentangle the effects of an intervention from changes that might have occurred anyway. We argue here with others that there is a need for mixed methods that combine advantages of both (Voils, Sandelowski et al., 2008, White, 2008).

2. Objective of the study

The aim was to measure the impact of the RAD CBR program on the main outcomes of interest of the World Health Organization matrix (World Health Organization 2010): health, education, livelihoods, social participation and empowerment.

2.1 Effectiveness and monitoring the program through quantitative data collection

- **Our objective is to identify any differences the CBR interventions implemented by RAD are making in the lives of persons with disabilities.** Such feedback will help strengthen and guide future directions of the program by documenting the achieved outcome. Similarly, it will allow RAD staff and managers revisiting processes and choices, and adopt the changes that are necessary to address possible identified limitations. It will also help the RAD team argue the programme substance and significance with donors and stakeholders such as BPHS implementors and Government.
- We aim at developing a methodology that is simple and straightforward: the instrument is short and easy to administer (interview lasts 20 to 40 minutes), data entry **requires ten minutes per form, and the information collected allows to report on achievement and should replace existing more complex and unfriendly procedures.**

Our research project aims to contribute towards filling existing gap about CBR programmes, using both an original methodology and a valid and reliable easy to use measurement tool to explore the programmes’ impact. This project comes in a timely manner as it meets the current concerns of

WHO to collect more information about CBR in order to test the new version of the WHO manual on CBR as well as addressing the need for more knowledge about ways of ensuring equal opportunities for persons with disabilities, as emphasised by the recently ratified UN Convention of the Rights of Persons with Disabilities (United Nations 2006).

Firstly, the research aims to understand and measure the overall role and impact of CBR in improving the quality of life of persons with different types of impairments as well as different demographic, social and economic backgrounds. Quality of life is determined by the freedom of people to do and to be what they value (Sen 1999). In other terms, we will investigate the effectiveness of CBR programmes in improving the control persons with disabilities have over their daily lives, participating in different aspects of community life (i.e. combating stigma and prejudice), and accessing various services, over the five domains of the CBR matrix (health, education, livelihood, social and empowerment). Furthermore, we will examine to what extent persons with disabilities benefiting from the CBR programmes are improving their socio-economic conditions, and therefore escaping from multidimensional poverty (understood here as a deprivation of basic capabilities such as life expectancy, infant mortality, the ability to be well nourished and well sheltered, basic education, employment and health care (Sen 1992).

The information gathered will feed a more ambitious objective of monitoring and evaluating fieldwork through a capability lens which primarily focuses on enhancement of beneficiaries' opportunities. The overall outcome will be to allow for adaptation of the CBR programmes to people needs based on a regular and on-going monitoring.

2.2 Mechanisms at work with a more qualitative study

Secondly, we investigated the factors and mechanisms that constitute barriers to access of CBR activities and support. The study should highlight whether the CBR programmes are completely inclusive of all groups of individuals with disabilities, as well as if they transfer knowledge about disability and rehabilitation skills.

Thirdly we explored the management and the implementation of the CBR programmes, as well as the sustainability of CBR projects. An important question was whether the CBR programme is perceived as being participatory by the beneficiaries enough - do persons with disabilities and their organisations and families have a say in the planning, decision making, implementation process and evaluation of the projects? We appraised the utilisation of available resources in the community in the functioning of the programmes. Understanding the different issues surrounding CBR as perceived by persons with disabilities using a qualitative method is a rather innovative approach.

3. Methodology for the quantitative approach

3.1 Sample design

For the present study, we interviewed all new 1680 CBR participants included in the CBR program between July 2012 and December 2013 (see Figure 1 in Appendix). Besides living in one of the 169 villages or urban areas called mahals of the catchment area of the program, the other inclusion criteria were the one defined by the CBR program at its start in 2004. At the creation of the program, catchment areas were defined under the following criteria: i) The number of persons screened with a disability using a locally developed, tested and validated questionnaire based on World Health Organization guidelines for grassroot disability program to account for contextual factors (World Health Organisation 1989) living in the areas or mahal closed to the other SCA activities such as orthopedic workshops and physiotherapy centers/clinics.; (ii) mahals had to be the place of

residence of the newly recruited CBR workers before the program could expand progressively to nearby villages until covering the whole district; iii) the willingness of the person with disabilities and the family members to participate in the CBR programs; iv) the readiness of a family member to be trained by - and implement - the activities set up by the CBR worker in order for such activities to be ongoing daily, while the CBR worker would check progress made on a weekly or sometimes bi-weekly basis; v) the absence in the mahal of a similar intervention by any other organization, and vi) the intervention had to be welcomed by the overall village community and particularly the village council or shurah. On average, one CBR worker was serving 100 participants with disabilities per year. Each expansion was decided in agreement with the CBR program management and the new targeted areas were surveyed for identification of persons with disabilities using the same WHO instrument (World Health Organisation 1989).

Controls were randomly selected during the same period in villages and urban areas of the same provinces but outside of the catchment area of the CBR program. We used a random number generator to select a first village to include in the sample from the complete list of villages in each region. The subsequent villages were then selected from the list at the sample interval. This process was repeated for all 13 provinces in the study to compile the full list of 100 control villages. 60 households were randomly selected in each village for a total of 6000 households in the sample. In the social centre of the village, typically a mosque or an open square, a child was asked to select a number from a small bag, and to spin a spinner. The spinner indicated the direction from which the survey party would begin the survey. Households were selected using the nearest front door method. A household was defined as a unit that shared a kitchen, an income and occupied the same flat, house or compound. All heads of households were interviewed with a locally validated disability-screening tool composed of 34 items for adults (DSQ-34) and 35 for children (DSQ-35) to identify all members of the household with disabilities (Trani, Babulal et al. 2015). All study participants were interviewed with a locally developed and validated questionnaire that inquired about demographic characteristics, socioeconomic status, access to rehabilitation, health and social services, individual functioning, social participation, and additional needs. The questionnaire examined the effectiveness of the CBR program in improving the power of persons with disabilities to determine their daily lives, participate in different aspects of community life, escape stigma and prejudice, and access various CBR services from among the five domains of the CBR matrix (health, education, livelihood, social inclusion and empowerment) (World Health Organization 2010). Disability experts in Afghanistan were asked to review the content of the initial English version of the tool for completeness, content validity, and appropriateness of the questions to the Afghan cultural context. The English version of the tool was then translated into Dari and Pashto by a disability expert from the Ministry of Public Health in Kabul. Several different translators worked independently to back-translate the survey into English, and compared results to reconcile discrepancies. A first version of the questionnaire developed by the authors was initially tested end of 2011 with a group of 20 CBR participants in Jalalabad, Nangarhar, Afghanistan. Each respondent was interviewed separately by a researcher for consistency check in responses provided. Additionally, the Dari and Pashto versions of the final questionnaire were tested through a series of 30 interviews in Kabul in 2012 with persons with disabilities of different age groups, gender and ethnicity to verify that response process followed, understanding and interpretation of complex or technical terms, such as access to healthcare, available CBR services, participation in family and community activities, and measures of additional need and satisfaction with life were consistent across different socioeconomic background and with the initial concepts conceived in English by the researchers. Respondents were asked the questions as defined by researchers followed by a series of probe questions aiming at capturing their understanding of the questions in light of their own life experience (DeMaio and Rothgeb 1996). All study participants were interviewed with the same tool three times between July 2012 and December 2013, between July 2013 and December 2014 and finally between July 2014 and December 2015. Attrition rate was 29% and 8.6% between round 1

and 3 respectively for participants and controls. Reasons for attrition are as follows: death or migration outside of the catchment area of the study. Refusal to participate in the study was very minimal among participants ($n=14$, 0.01%) and higher among controls ($n=173$, 15.3%). Yet, there was no significant differences between respondents and non-respondents with respect to the measured characteristics and we therefore assumed that unobserved data were missing at random (Little and Rubin 2014).

3.2 Statistical framework

To explore the impact of CBR on a population of persons with disabilities in a given area who entered the programmes, we propose to use a statistical framework for causal inference which has received increasing attention in recent years - the framework based on potential outcomes. This framework is rooted in the statistical work on randomized experiments by Fisher and Neyman (Neyman 1923), and extended by Rubin (Rubin 1974) and subsequently by others to apply it to nonrandomized studies and other forms of inference. This perspective was called “Rubin’s Causal Model” because it viewed causal inference as a problem of missing data, with explicit mathematical modelling of the assignment mechanism as a process for revealing the observed data (Holland 1986). The RCM allows the direct handling of complications, such as non-compliance with assigned treatment (which bridges experiments and the econometric instrumental variables methods) (Angrist, Imbens et al. 1996). In the late 1980s and 1990s, many economists have accepted and adopted this framework as well because of the light it sheds on questions of causality (Manski and Thompson 1986, Bjorklund and Moffitt 1987, Angrist and Imbens 1995).

Here we describe the main elements of this modern approach to program evaluation.

Suppose we wish to analyze a CBR program using observations on n disabled people, indexed by $i = 1, \dots, n$. Some of these individuals were enrolled in the CBR program. Others were not enrolled, either because they were not yet eligible and on a waiting list (e.g. the village was not reached by the program) or chose not to enrol. For each unit we also observe a k -dimensional column vector of covariates (or pre-treatment variables).

After setting a response variable, on which we want to measure the impact of the CBR program, we postulate, for each individual i , the existence of two potential outcomes, usually denoted by $Y_i(0)$ and $Y_i(1)$. The first, $Y_i(0)$, denotes the outcome (i.e. the value of Y_i) that would be realized by individual i if he or she did not participate in the CBR program. Similarly, $Y_i(1)$ denotes the outcome that would be realized by individual i if he or she did participate in the CBR program. The causal effect of the active treatment relative to its control version is defined as a comparison of $Y(1)$ and $Y(0)$.

In randomized experiments, the results in the two treatment groups may often be directly compared because if the size of the groups is sufficiently large their units are likely to be similar. In the case of a CBR program the experiments is nonrandomized, and such direct comparisons may be misleading because the individuals exposed to the CBR program can differ systematically from the individuals not exposed. In other words, people with disabilities joining the CRB program might somewhat be self-selected, and so large differences may exist between the treatment and control groups on observable as well as unobservable covariates, which can lead to biased estimates of treatment effect. Therefore, additional assumptions have to be made to estimate the causal effects of interest. An assumption often made in such a study is the “strong ignorability” or “unconfoundedness” of the assignment mechanism given the observed covariates, which requires that all variables that affect both outcome and the probability of receiving the treatment are observed.

When there are many background covariates, as in our study, balancing the distribution of all the covariates between treated and control groups can be difficult. To address this problem Rosenbaum and Rubin (1983) developed the “propensity score” methodology. The key insight of their work was that given the strong ignorability assumption, treatment assignment and the potential outcomes are

independent given propensity score. Thus, adjusting for the propensity score removes the bias associated with differences in the observed covariates in the treated and control groups. To estimate propensity scores, which are the conditional probabilities of being treated given a vector of observed covariates, we must model the distribution of the treatment indicator given these observed covariates.

Much of the work on propensity score analysis has focused on the case where the treatment is binary. In our specific framework, it also would be natural to follow this approach, comparing treated individuals and control individuals. To account for the heterogeneity of the population, non-treated people with disabilities being potentially very different to the others with respect of many characteristics, we will need a big enough sample to avoid difficulties in finding a common support for the identification of a causal effect.

To manage this possible negative aspect of this specific impact evaluation of CBR programs is to consider a continuous treatment approach, allowing the treatment (i.e. CRB) to take on a continuum of values. The key feature of the data is then the fact that the treatment duration varies. The evaluation question that corresponds to the continuous administering of the rehabilitation is then how effective (relative to each other) is the CBR program with different durations? This assessment of the dynamics of treatment duration essentially amounts to estimating a dose-response function. In this work we then aim to estimate the responses (measured on variables of interest) that correspond to specific values of continuous doses (i.e. being under the program for a specific length of time).

Since doses are not assigned under experimental conditions, estimation of a dose-response function is possible using the generalized propensity score (GPS). The GPS for continuous treatments is a straightforward extension of the well-established and widely used propensity score methodology for binary treatments introduced above, and multi-valued treatments (Imbens 2000). This methodology is developed in Hirano and Imbens (Hirano and Imbens 2004) and Imai and van Dyk (Imai and van Dyk 2004). To our knowledge, our work would be one of the few applications of the GPS in the context of evaluating community-based rehabilitation programs on disabled people.

Another method we will use is the event-history approach to program evaluation, which is firmly rooted in the econometric literature on state dependence and heterogeneity (Heckman and Borjas 1980).

In particular, if we consider the duration of the treatment as identified by two moments in time indexed with t_1 and t_2 , all the disabled people that are still under a CBR program at the time of the interview share the same value of t_2 . For this subgroup of people is then possible to generalize the method proposed by Abbring and Van den Berg (2003) where the treatment and the outcome are dependent on the moment they occur, and these instants in time are realizations of stochastic processes with dependent unobserved variables (Abbring and van den Berg 2003). This approach exploits information on the timing of the treatment relative to the outcome that is generally discarded in binary treatment analyses.

3.3 Ownership of Data / Results

Information and results from the data collected will be used in academic articles and publications in agreement with SCA. Yet, The findings, interpretations and conclusions expressed in reports and papers are entirely those of the authors and cannot be attributed in any manner to SCA or affiliated organizations. Analysis from the research produced by Trani and Gall can be used by RAD for donor reports and proposal.

4. Preliminary Phase: July 2012-December 2013

4.1 Training – 3-4 days (for CBR staff in two project offices (Taloqan and Jalalabad) with representative from MPO and GPO attending.

A week training explaining the project, the tool and rules for data collection will be carried out in Taloqan and Jalalabad. Participants were identified in each of the four RAD regions using the "Training in the community for people with disabilities: Guide for Local Supervisors" of the World Health Organization (World Health Organisation 1989). We will carry field test of the trainees to check for understanding of the study and quality of the data collection. The community mobilisation field supervisors will be trained on supervision of files and data entry.

4.2 Pilot Survey – 2-4 days

Following the training, the study process and instruments were pilot tested in one region. The data collection procedures and quality of forms were checked for content and face validity. The disability questionnaire was also validated (Trani, Babulal et al. 2015).

4.3 Data Collection and entry procedures

Overall supervision- The supervisors check questionnaires and send them back (including going with data collectors) when there are mistakes. Supervisors know Dari and Pashtu or would check using the English form as well. A template for data entry has been prepared using the questionnaire in Epidata software and training provided for four data entry operators. All survey forms will be collected and sent to local data operator who will be identified in country. The database will be sent to the PI monthly through a protected intranet for ultimate data check.

5. Phase 2 – Data collection, data entry and analysis for the pilot survey

Participants are persons with disabilities of all ages participating in the Rehabilitation for Afghans with Disabilities (RAD) community-based rehabilitation program covering 13 provinces of Afghanistan. The control group was composed of persons with disabilities of all ages on a waiting list for participation and living in the same 13 provinces of Afghanistan where the RAD program is implemented. There are theoretically no over inclusion criteria over than having an impairment and to be listed for enrolment in the program. Potential new participants randomly selected on the waiting list are interviewed during the same period of time.

The RAD program includes several thousands of persons with disabilities, although the exact figure is not available. The pilot study will interview participants at starting and finishing time of participation. The tool used is supposed to be a monitoring tool used for the staff to gather information about the intervention.

5.1 Data collection

The number of respondents was 1860 participants and 1133 controls.

CBR workers involved in data collection interviewed one or two new participants per week, for a period of 18 months (July 1st 2012 until December 31st 2013).

The duration of interview was 20-40 minutes, between half an hour and an hour of work per week for each CBR worker involved. Each interview would last between 20 and 40 minutes depending on the complexity of the individual situation, and the capacity of the participant to respond (i.e. it might be

longer with a person with learning disability or a child who need the help of a proxy respondent in the family).

Data collection continued afterwards as part of the CBR process to provide day to day information on participants progress. Participants were interviewed with the same tool once a year until discharge and maximum three times (baseline, midline and endline).

5.2 Data entry

- Questionnaires were entered into Epidata® a free software programme which requires little knowledge to be used.
- Data entry was carried out either by each CBR worker for his/her own forms, or by any staff with basic knowledge in computer on a monthly basis at the RAD regional
- Each form requires between 5 and 7 minutes to be entered. A total of 8 forms per CBR worker per month require only 1 hour of work
- Database was sent monthly by the PI for preparation of the quarterly fact sheets and other analysis

5.3 Analysis Quarterly Fact sheet and impact evaluation

- Follow up of data entry every 3 months by JF Trani who will provide a fact sheet with major indicators in tables and graphs as a monitoring tool of the RAD intervention to be used as a communication tool with DPOs, donors, SCA management and other stakeholders
- More in depth analysis using propensity score matching (PSM) is carried out at the end of the data collection to evaluate the impact of the RAD program on participants

5.4 Endorsement and review

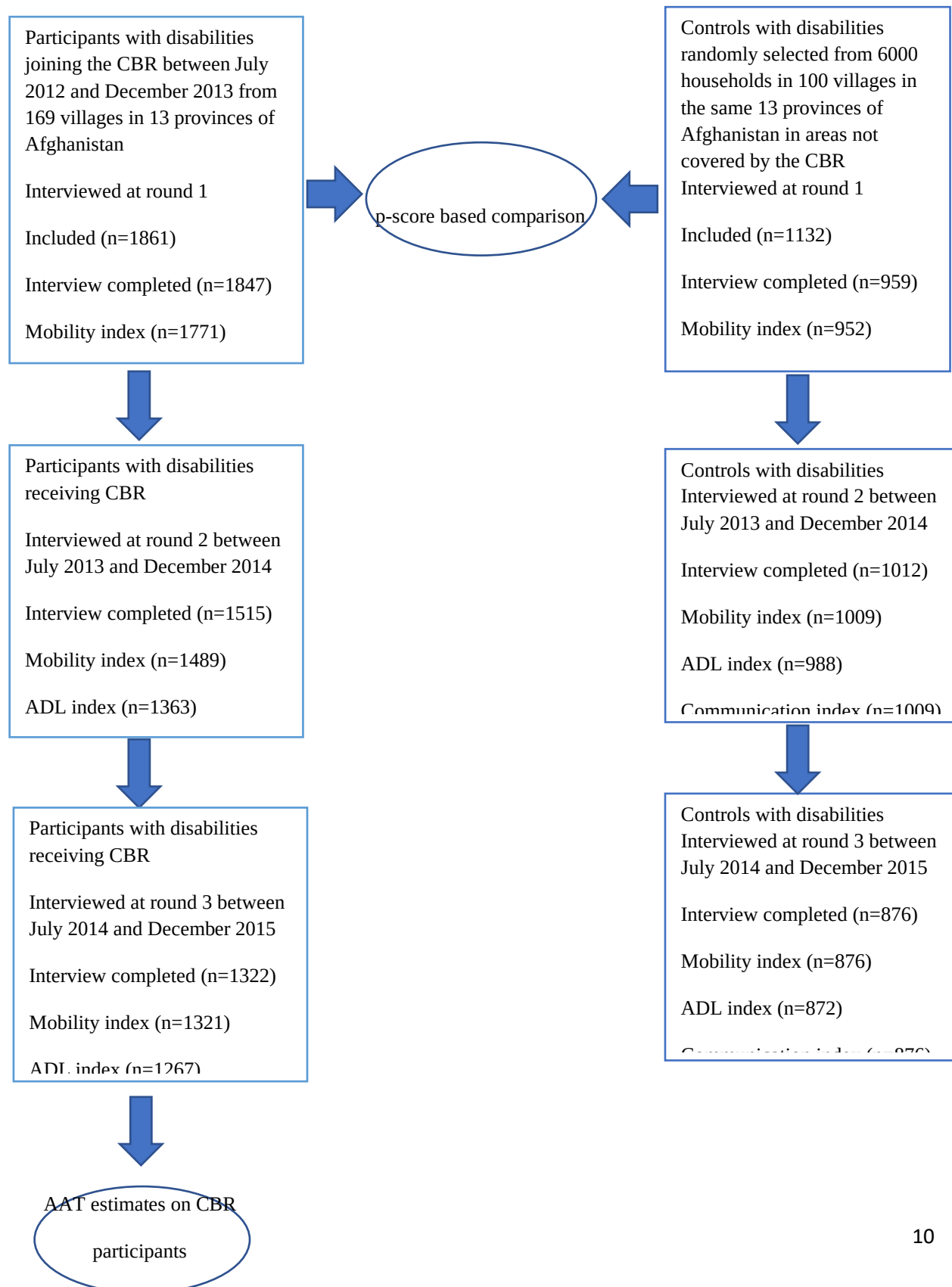
- The process was reviewed after 12 months and after 24 months to evaluate its usefulness for measuring the effectiveness of the RAD program as well as for constituting an easy and efficient monitoring tool for the staff.

6. Ethics

Ethical clearance was granted by the Ministry of public health (18/11/2012) and by Washington University in St Louis (12/12/2012).

7. Appendix

Figure 1. Study participants selection, intervention and follow up process



8. References

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