

# Model for Service Delivery for Developmental Disorders in Low-Income Countries

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## abstract

As in many low-income countries, the treatment gap for developmental disorders in rural Pakistan is near 100%. We integrated social, technological, and business innovations to develop and pilot a potentially sustainable service for children with developmental disorders in 1 rural area. Families with developmental disorders were identified through a mobile phone-based interactive voice response system, and organized into “Family Networks.” “Champion” family volunteers were trained in evidence-based interventions. An Avatar-assisted Cascade Training and information system was developed to assist with training, implementation, monitoring, and supervision. In a population of ~30 000, we successfully established 1 self-sustaining Family Network consisting of 10 trained champion family volunteers working under supervision of specialists, providing intervention to 70 families of children with developmental disorders. Each champion was responsible for training and providing ongoing support to 5 to 7 families from his or her village, and the families supported each other in management of their children. A pre-post evaluation of the program indicated that there was significant improvement in disability and socioemotional difficulties in the child, reduction in stigmatizing experiences, and greater family empowerment to seek services and community resources for the child. There was no change in caregivers’ well-being. To replicate this service more widely, a social franchise model has been developed whereby the integrated intervention will be “boxed” up and passed on to others to replicate with appropriate support. Such integrated social, technological, and business innovations have the potential to be applied to other areas of health in low-income countries.

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The past decade has witnessed an impressive increase in global mental health research leading to the development of evidence-based intervention packages that can potentially be integrated into existing health systems.<sup>1</sup> The question now facing the global mental health community is, “How can mental health care be made available at scale to populations with systems that have neither the means nor the expertise to deliver it?”<sup>2</sup> More than three-quarters of the world’s population lives in these circumstances, and even countries with

relatively greater resources struggle to meet the demand. Urgent solutions are required if the global health community seriously wants to tackle the rising burden of disease from mental disorders, currently estimated to be nearly 23% of global morbidity, more than any other group of disorders.<sup>3</sup>

The need for implementation research in low-income countries (LICs) has been highlighted,<sup>4,5</sup> but conventional health services research has been unable to overcome diverse bottlenecks, such as lack of mental

health professionals, chronic shortage of funds, weak health and social care systems, stigma attached to mental disorders, and a lack of will at the political and policy level.<sup>2</sup> We adopted a framework, developed by the Canadian Grand Challenges in Global Mental Health,<sup>6</sup> that defines implementation research in terms of social, scientific/technological, and business innovations that, combined together in a culturally acceptable and feasible manner, lead to an integrated innovation to assist scale-up of mental health in low-income settings (Fig 1). We describe findings from a project in rural Pakistan that used this framework to develop implementation strategies to provide care to children with developmental disorders (intellectual disability and pervasive developmental disorders). The project was carried out by a local nongovernmental organization, the Human Development Research Foundation (HDRF).

Ethical approvals were obtained from the local ethics review board at the HDRF, Islamabad, and Institute of Psychiatry, Rawalpindi Medical College, Rawalpindi, Pakistan. Informed consent was obtained before engaging the parents and their children into the project.

### THE SETTING AND THE CHALLENGES

Pakistan has a population of ~180 million people, of which three-quarters live in rural areas. Nearly 41 million people live on <1.25 USD (purchasing power parity) per day,

and more than 35% of all children younger than 5 are undernourished.<sup>7</sup> Sociopolitical problems and conflict in some areas have pushed Pakistan to the brink of a fragile state, and have seriously limited primary health care initiatives.<sup>8</sup> Public spending on health is low; in 2009 health care spending amounted to just over 1% of gross domestic product, of which <5% was allocated to mental health.

The prevalence of developmental disorder (intellectual disability and pervasive developmental disorders) is >7%.<sup>9</sup> Poor awareness of the condition in family members and front-line health providers leads to delay in recognition and appropriate management.<sup>10</sup> There is considerable stigma and discrimination affecting such children and their families. Specialist services are rare, concentrated in urban areas, and inaccessible to most. Thus, the treatment gap for developmental disorders in rural Pakistan is almost 100%.

### SOCIAL INNOVATION: FAMILY NETWORKS FOR CHILDREN WITH DEVELOPMENTAL DISORDERS

In the absence of specialist services, “task-shifting” has been recommended as a key implementation strategy for mental health.<sup>11</sup> A task normally performed by a specialist is transferred to a health professional with a different or lower level of education and training, or to a person specifically trained to perform a limited task only, without having a formal health education. For chronic conditions like developmental disorders, a major barrier to task-shifting in LICs is the lack, or weakness, of systems (health, social care, education) to which tasks can be shifted.<sup>12</sup>

We conducted qualitative studies in rural Pakistan to explore if task-shifting could be taken to its most proximal level (ie, families living

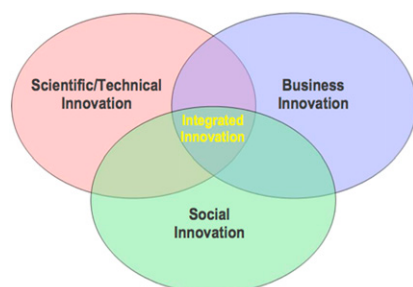
with a child with developmental disorder), thus creating a new system for intervention delivery.<sup>13</sup> The key finding was that volunteer family members of such children were willing to be organized into an active, empowered group within the community that (1) by using a task-shifting approach, could be trained and supervised by specialists to provide evidence-based interventions to their own children and to cascade it down to other families in their villages; (2) supported each other, with the more experienced and motivated “champion volunteers” providing peer-supervision to new family members who join the group; and (3) worked to reduce the stigma associated with the condition, and improve opportunities for participation in community life.

In a rural Pakistani population of ~30 000, we successfully established 1 self-sustaining Family Network consisting of 10 trained champion family volunteers working under supervision of more experienced trainers at the local nongovernmental organization (HDRF), providing intervention to 70 families of children with developmental disorders, including their own. Each champion was responsible for training and providing ongoing support to 5 to 7 families from his or her village, and the families supported each other in management of their children. The network members campaigned for better facilities for the children in local schools and primary health care centers, and pushed to improve participation in community life.

### SCIENTIFIC AND TECHNOLOGICAL INNOVATIONS

#### Identifying Families With a Child With Developmental Disorder by Using Interactive Voice Response Technology

The implementation of such networks at scale would require identification of families and potential champions.



**FIGURE 1**  
Framework for integrated innovation.

A house-to-house survey would not be sustainable at scale because of the cost and logistical challenges. Taking advantage of mobile phone access available to 85% of Pakistan's rural population, we applied technological solutions to this problem by developing an interactive voice response (IVR) system. The IVR system consisted of an automated telephony system that interacted with callers, gathered information, and routed calls to a database that could be accessed by a human at any time. With our local technology partners, we developed an IVR system suited to the local context, consisting of telephony equipment, a software application, a database, and supporting infrastructure. A leaflet with key signs of a developmental disorder, a motivational message, and a free phone number was distributed to every household in 1 rural area (population 30 000) through local community health workers. When dialed, the IVR application provided prerecorded voice-responses to the Ten Questions Screen for disability.<sup>14</sup> After each prerecorded question had been read out, the caller was given the choice to select options by pressing a digit. When all 10 questions had been answered, the application used an algorithm to determine the results of the screening and fed it back to the caller. Callers who screened positive for developmental disorders were asked to leave their address and contact number, and whether they were willing to be contacted. This information was used to cluster families into 10 networks within villages and neighborhoods and identify a champion for each network. The IVR system was able to identify 92 (84.4%) of 109 children aged 2 to 9 years with developmental disorders (identified through a house-to-house survey by using the Ten Questions Screen) resident in 1 rural area (population 30 000). Following a one-off cost of US\$50 000 to develop the system, the cost of identifying a child

with a developmental disorder was US\$0.07, compared with a cost of US \$7.0 of identifying a child through a house-to-house survey.

### Training Champions to Deliver Evidence-Based Intervention: Avatar-Assisted Cascade Training for Developmental Disorders

We used the World Health Organization's (WHO) mental health gap intervention guide (mhGAP-IG),<sup>15</sup> providing comprehensive evidence-based guidelines for intervention in this target group, as the scientific basis of our champion-delivered intervention. A detailed discussion of the scientific basis for the mhGAP guidelines is beyond the scope of this article, but can be found elsewhere.<sup>16</sup> Briefly, WHO established a Guideline Development Group in 2008 to develop evidence-based recommendations that adhered to the Grading of Recommendations Assessment, Development and Evaluation principles for developing transparent, evidence-based WHO guidelines.<sup>17</sup> By using this methodology, the group systematically synthesized and appraised the evidence base for interventions, leading to the publication of the mhGAP-IG.

Although the mhGAP-IG provides guidelines for what to do, it does not specify how to do. To overcome this challenge, we developed a standardized, intuitive tablet-based training and intervention-delivery tool. The mhGAP-IG diagnostic and management guidelines were

incorporated into "real-life" narratives of the lives of 3 children with developmental disorders, "Bano," "Babloo," and "Beena," their family members, and other supporting characters. The guidelines were broken down into training scenarios, which were converted into narrative scripts by a panel of experts. An artist converted the characters into "Avatars" (graphic image representing each character) (Fig 2), which were used to voice the narrative scripts. The narratives were interactive, with pause buttons and instructions, allowing family members to discuss each scenario in the context of their own lives, develop individualized management plans for their child based on the information provided, practice parent-management skills through role play, discuss ways of increasing participation in communal life, and share problem-solving strategies. The training scenarios were organized into modules covering every aspect of the guidelines (psycho-education; parent skills training, including care for development; physical health, including nutrition advice; parental stress; community participation; stigma and rights). The training scenarios can easily be updated, modified, or added to without disturbing the overall architecture of the software. We called this system Avatar-Assisted Cascade Training (ACT).

A trainer at HDRF (master's in psychology, with a year's clinical



**FIGURE 2**  
Tablet-based ACT system.

experience of developmental disorders), using the ACT system, trained the champions, and they, in turn, used the same devices to cascade the training down to 5 to 7 families allocated to each champion. The training took 8 days to complete, but the champions and the families continued to meet regularly to support each other. The champions were supervised once a month by an experienced trainer at HDRF, who in turn was supervised by a specialist. A paper-based manual of the adapted mhGAP intervention guide in Urdu is available at [www.hdrfoundation.org](http://www.hdrfoundation.org) and an English version will be available soon.

We evaluated the impact of ACT through a pre-post Knowledge, Attitudes and Practices questionnaire (15 items with a total score of 30). We found that the training led to a significant improvement in scores of family members trained ( $n = 24$ ) from a baseline of  $23.29 \pm 3.22$  to after training  $27.17 \pm 2.11$  ( $t = 8.36$ ,  $P < .001$ ).

### Monitoring Outcomes: Mobile Information Management System

We used a measure of functioning, the WHO Disability Assessment Schedule for children (WHODAS-Child) validated for use in low-income settings,<sup>18</sup> and culturally adapted for use in rural Pakistan, as our outcome tool. The scale measures 6 domains of functioning through 34 questions answered by using a Likert-type scale.

To make routine data collection sustainable, the scale was integrated into the ACT system and administered by the champions to families under their care. It was therefore designed to be simple and user-friendly. Each question was accompanied by an illustration and an audio voice-over that could be repeated (Fig 3). The Likert-scale response was converted into a visual scale with touch-sensitive slider scale. Each family completed the



**FIGURE 3**  
Integrated outcomes assessment: tablet-based WHODAS-Child item.

WHODAS-Child at baseline, and then at regular intervals of 3 months. These data were stored in the tablet, and transferred to a central server located at HDRF in 2 ways. First, if the tablet was connected to the Internet, the champion could log on to the server and upload the completed questionnaires. If the champion did not have access to the Internet, the champion could upload the completed questionnaires when he or she visited the center for supervision.

The data generated served a number of purposes. It allowed family members and champions to visually gauge progress of each individual child over time, and discuss domains where progress was slow. It helped with supervision of the champions, allowing the supervisors to identify problem areas and discuss potential solutions that they could take back to the families. Finally, the aggregated data allowed HDRF to monitor the overall quality of the program.

We conducted an evaluation of impact of the intervention on a number of child and family outcomes using a pre-post design (Table 1). Analysis of data collected from families that had the program for 6 months ( $n = 68$ ) indicated that all had received the 8-day training from their designated champions, and there was a significant decrease in WHO-DAS global disability score in their children from baseline ( $56.89 \pm 22.02$  to  $50.57 \pm 24.62$ , 95%

confidence interval [CI] 3.63 to 9.0;  $P < .001$ ). The only 2 domains where there was no significant improvement were social relationships and participation. This might be expected, given that the intervention had been delivered for only 6 months and these domains would probably require a longer period of follow-up to show discernable change. There was also a reduction in parent-reported socioemotional difficulties scores in the child ( $19.67 \pm 5.24$  to  $13.40 \pm 4.76$ , 95% CI  $-7.68$  to  $4.87$ ;  $P < .001$ ). The families appeared to be more empowered to engage with services and community resources for their child after the intervention, and had modest improvements in their perceptions of stigma.

The magnitude of change in child outcomes is clinically meaningful. For example, the change of 6 points on the total difficulties score is superior to other parenting studies conducted through specialists in high-income settings. Fujiwara and colleagues<sup>19</sup> demonstrated a reduction of the total difficulty score from 12.2 to 10.6 resulting from a positive-parenting program in Japan, whereas in another intervention among preschoolers in the United States, scores dropped from 12.6 to 10.8.<sup>20</sup> However, the results need to be interpreted with caution, as the pre-post nonrandomized evaluation has many weaknesses (eg, can show only short-term changes; cannot account for preexisting trends; is weak at ruling out other alternative explanations). Nevertheless, these results indicate strong trends toward a positive impact. It should be borne in mind that the intervention is based on WHO mhGAP guidelines that are evidence-based,<sup>16</sup> and the positive outcomes indicate that the integrated innovation in implementation is producing change in outcomes in the right direction. Further robust evaluation (through randomized controlled trial design) of scaled-up programs would



**TABLE 1** Summary of Key Outcomes at 6-Month Follow-up (*n* = 68)

Variable	Score at Baseline		Score at 6 mo		<i>P</i>	95% CI	
	Mean	SD	Mean	SD		Lower Limit	Upper Limit
Child functioning <sup>a</sup>							
Understanding and communication	61.62	21.65	54.78	24.82	.001	2.90	10.77
Getting around/mobility	42.99	39.77	36.91	41.03	.000	3.02	9.14
Self-care	61.21	28.58	49.17	31.66	.000	7.54	16.53
Getting along with others	50.36	29.92	45.51	28.69	.087	−0.72	10.42
School and nonschool activities	81.62	17.29	74.50	24.45	.000	3.77	10.45
Participation in society	43.51	22.32	42.54	23.40	.72	−4.43	6.38
Global Disability Score	56.89	22.02	50.57	24.62	.000	3.63	9.0
Socioemotional difficulties in child <sup>b</sup>							
Total difficulty score	19.67	5.24	13.40	4.76	.000	−7.68	−4.87
Family stigma <sup>c</sup>							
Stigmatizing experiences score	1.95	1.78	1.41	1.47	.017	0.10	0.97
Family empowerment <sup>d</sup>							
Family	3.89	0.57	4.00	0.58	.087	−0.22	0.02
Services	3.50	0.82	3.93	0.77	.000	−0.63	−0.25
Community involvement	2.48	0.83	2.90	0.88	.000	−0.62	−0.20
Caregiver well-being <sup>e</sup>							
Total well-being score	44.12	21.74	44.06	19.65	.98	−6.03	6.15

<sup>a</sup> WHODAS–Child version<sup>18</sup>: Parent rated, 34 items distributed across 6 domains to measure functional impairment in children. Each item is rated on a 5-point Likert scale (0 = no functional impairment, 4 = extreme impairment/cannot do). Global Disability Score (range 0–100) is estimated by averaging domain scores.

<sup>b</sup> Strength and Difficulties Questionnaire<sup>26</sup>: Parent rated, 25 items distributed over 5 domains: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. Each item is rated on a 3-point Likert scale (0 = not true, 1 = somewhat true, 2 = certainly true). Total difficulty score is calculated by adding the scores of 25 items.

<sup>c</sup> Inventory of Stigmatizing Experiences (Family version)<sup>27</sup>: Interview-based measure of the extent and impact of stigma faced by family. Seven items, each item is rated on a 5-point Likert scale (1 = never to 5 = always). The responses are recoded into a binary variable with 1 reflecting presence of stigma and 0 reflecting absence of stigma. Scores are summed across all items with a maximum score of 7, with lower scores indicating relatively less stigma.

<sup>d</sup> Family Empowerment Scale<sup>28</sup>: Parent rated, 34 items consisting of 3 subscales: The family subscale (12 items) refers to the parents' management of everyday situations. The service system subscale (12 items) refers to parents' acting to obtain services to meet the child's needs. The community subscale (10 items) refers to parents' advocacy for improving services for children in general. Each item is rated on a 5-point Likert scale (1 = not true at all to 5 = very true). Scores are summed across all items for each subscale with higher scores indicating relatively more empowerment.

<sup>e</sup> WHO-5 Well-Being index<sup>29</sup>: Self-rated by parent, 5 items measuring overall quality of life, satisfaction with health, daily activities, relationships, and living conditions. Each item is measured on a 6-point Likert scale (0 = low score to 5 = high score). Raw scores are calculated by summing the scores ranging from 0 to 25. The score is multiplied by 100 to get a percentage score, higher score indicating greater well-being.

provide definitive evidence for effectiveness of the integrated innovation.

There was no change in the caregivers' well-being scores, indicating that the burden of care from the intervention was not having a negative impact on the caregivers' well-being. This was an important finding, because programs that advocate family-led home-care for children with disability have been criticized for contributing to increased stress and reduced quality of life in the primary caregiver.<sup>21</sup>

Although the preliminary results are positive, the program was not

without its challenges. The study was conducted in socioeconomically deprived settings where the population had many unmet needs. Some participants expected practical or financial support from the organization, especially when their children had significant comorbid physical needs. The motivation of some mothers to remain engaged with the program was also affected by the limited amount of time they could spend away from home due to multiple child care and other domestic responsibilities. Such demands also came in the way of giving exclusive attention and time

to the child with the developmental disorder. Some key messages, such as discouraging marriage within the family, were not well received, and there was scope to improve the narratives and illustrations. Finally, longer-term motivation of champions could not be assessed beyond the follow-up period of 6 months. To be sustainable in the longer term, we felt the program would need to ensure that (1) the intervention continued to be perceived to be useful, (2) the champions' training and supervision was responsive to the families' needs, and (3) the champions were appropriately incentivized and supported.

## BUSINESS INNOVATION: THE SOCIAL FRANCHISE MODEL

To replicate this model more widely, HDRF has developed a social franchise model whereby it will work with organizations, both governmental and nongovernmental, to deliver the program in units of 30 000 (the approximate population of a Union Council, the smallest geographical and administrative unit of population in Pakistan). Social franchising is based on the approach commercial franchises use to expand their branches. The proven business model is boxed up and passed on to others to replicate with appropriate support.<sup>22</sup> In our model, each franchisee will sign an agreement to provide a master trainer who will be trained in ACT and supervision by HDRF, provide the cost of tablet devices, and facilities for training and supervision of champions identified through the IVR system. HDRF will set up all systems for the franchisees free of cost, and continue to be an umbrella organization, monitoring and improving quality.

It is recognized that this model of service delivery relies on a grass-roots organization that is well embedded in the community and has the capacity to manage the

technological aspects of the program. In settings in which such organizations do not exist, it would be difficult to extend the model to the community. Here, the establishment of such organizations and building their capacity to deliver the innovation would be a necessary first step. However, it is also clear that in most low- and middle-income countries, nongovernmental organizations are the main source of support for children with intellectual disabilities,<sup>23</sup> and these organizations are often overwhelmed by the sheer numbers that require their assistance. The integrated innovation provides a feasible and effective way to deal with such challenges by empowering parents and communities to work collaboratively on a self-help basis.

The technological aspects require expertise and one-off costs to develop the “back-end” software that runs the ACT and mobile information management (MIM) systems. However, once developed, the same software can be used in other settings and countries. The “front-end” adaptations for cultural and contextual relevance, for example with the illustrations and narratives, are simple and inexpensive to carry out. Such adaptations can be informed by rapid qualitative research by using established methodologies.<sup>24,25</sup> Nevertheless, the innovation is not without some start-up and running costs, and policy makers would need to factor these into their planning. Small demonstration projects, such as the one described here, could help build capacity and confidence in implementers and policy makers, before scale-up. Table 2 outlines the steps required to replicate the model in new settings.

## FUTURE DIRECTIONS

By using the social franchise model, the HDRF is planning to scale-up the integrated model of service delivery

**TABLE 2** Steps Required to Replicate Innovation in Other Settings

Step	Action
1. Identification of area and suitable implementation organization	Identify and map suitable area (30 000–50 000 population) with an organization working in child health for a pilot project. Establish such an organization if it does not exist.
2. Assessment and building of capacity	Assess and build capacity of the organization to deliver the integrated innovation. Develop a dedicated team of 3 persons, including a Master trainer (Master's level with experience working in child health), a field coordinator, and an information technology technician.
3. Adaptation of ACT and MIM systems to local culture and context	Use rapid qualitative methods to inform the process of translation and adaptation.
4. Identification of families and champions	Install and run the IVR system to identify families with children with developmental disorders and potential champions. Develop family networks.
5. Training of champions	Train champions to deliver the intervention by using the ACT and MIM systems.
6. Supervision and monitoring	Conduct monthly supervision of champions. Monitor outcomes by using the MIM data.
7. Scale-up	Using a franchise model, scale-up the program to the next level.

to a population of 1 million. We have identified a number of potential local franchisees. From the current network of 70 family members, 15 have volunteered to offer their time to train others. Thus, the more experienced champions and trained family members have the potential, and the necessary capacity, to become trainers and supervisors for the new champions. This cascading model, whereby the program is rolled out sequentially to new Union Councils, will lead to an expanding pool of trained human resource that is potentially self-sustaining. The technological tools for identification, training, and monitoring have been fully developed and tested and are ready for rollout and will not incur additional cost, except for tablet devices, quality assurance, and support, that will be provided by HDRF. We recognize that larger scale-up and replication of this model remains an aspiration, but this small-scale project demonstrates that advances in information technologies offer solutions to problems that seem hitherto insoluble.

Although described for this specific group of neglected disorder, the

suggested model of service delivery has the potential for application to other areas of mental health. The whole field of mental health in LICs suffers from implementation bottlenecks previously described, and the political will to invest in this area remains low, while the need continues to grow exponentially. Innovative solutions from the social, technological, and business domains as illustrated in this project will need to be incorporated into the framework of implementation research to make scale-up of such mental health interventions a real possibility.

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## ABBREVIATIONS

ACT: Avatar-assisted cascade training  
 CI: confidence interval  
 HDRF: Human Development Research Foundation  
 IVR: interactive voice response  
 LIC: low-income countries  
 mhGAP-IG: mental health gap intervention guide  
 MIM: mobile information management  
 WHO: World Health Organization  
 WHODAS: World Health Organization Disability Assessment Schedule

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