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# Workshop for ASHAs on 3Ds: Birth Defect , Development Delays, and Disabilities and Inclusion of grassroots data in policy design

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**Date: 3 March 2023**

**Venue: Gumballi PHC, Karnataka IN (9am-2pm)**

**Organised by:**

**Dr Mohua Chakraborty Choudhury &  
Dr Pragya Chaube**



# Organising Team

## Core Team

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## Collaborators

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# Introduction

This report presents a comprehensive analysis of the workshop titled “Workshop for ASHAs on 3Ds: Birth Defect , Development Delays, and Disabilities and Inclusion of grassroots data in policy design” organised by Dr. Mohua Chakraborty Choudhury and Dr. Pragya Chaube in collaboration with the Center for Training Research and Innovation in Tribal Health (CTRITH), Indian Institute of Public Health Bangalore (PHFI), and the Department of Science and Technology, Centre for Policy Research, Indian Institute of Science (DST-CPR IISc). The workshop was held at Primary Health Centre at Ghumabali, in rural Karnataka for community health workers on the 3rd March 2023.

The workshop focused on addressing the challenges associated with the identification, data recording, and communication of three out of four critical areas emphasised by the Rashtriya Bal Swasthya Karyakram (RBSK). RBSK was launched in February 2013, by the Government of India, under the National Health Mission which aims for early child health screening and early intervention and strives to provide comprehensive, systematic healthcare services to children aged 0-18 years, with particular emphasis on early identification and management of birth defects, diseases, disabilities, and developmental delays (4Ds). The program encompasses various health interventions, including screening, diagnosis, treatment, follow-up, and referral services (Rashtriya Bal Swasthya Karyakram, MoHFW).

The workshop aimed to gather insights from Accredited Social Health Activists (ASHAs) workers, who are key stakeholders in the Indian healthcare delivery system. The Indian healthcare system functions at three levels: Primary, Secondary, and Tertiary. At the primary level, Accredited Social Health Activists (ASHAs) play a crucial role in directly serving the community. The ASHA is a scheme launched by the Government of India in 2005 as a part of the National Rural Health Mission, which has now been subsumed under the National Health Mission. ASHA workers, who are women aged 25-35 years from local communities, receive training to provide basic healthcare services, promote health awareness, facilitate access to healthcare facilities, and disseminate information about government health schemes. ASHAs are the initial point of contact for basic healthcare services for the people living in the rural areas. The scheme was introduced to address the gaps in primary healthcare delivery and improve the overall health outcomes in rural areas of the country.

Given the pivotal role of ASHA workers in bridging the gap between the healthcare system and local communities, their grassroots experiences and insights are invaluable for improving the overall health outcomes in rural areas. Through this workshop, a thorough analysis was conducted to understand better the grassroot experiences and challenges faced by ASHA workers. ASHAs play a crucial role in the RBSK program as they help in screening of newly born during home visits, conducting surveys and health camps, and encouraging families to participate. They provide health education to families, addressing misconceptions. ASHAs facilitate referrals to healthcare facilities, at times accompanying the family member to the nearest Primary health care centre therefore, ensuring continuous care and follow-up visits. They also maintain accurate records and update the RBSK database, aiding in program monitoring. The findings and recommendations presented in this report contribute to the ongoing efforts to strengthen rural healthcare systems and policies by incorporating grassroots data and the perspectives of frontline healthcare workers to improve the overall health outcomes and well-being of children across the nation.

ASHA workers are the pillars of the healthcare system in India, particularly in rural and remote areas where healthcare access is limited. They serve as a crucial link between the community and the healthcare system, playing a vital role in improving access to healthcare services, promoting health education and awareness, and providing basic healthcare services to the community. ASHA workers are uniquely positioned to identify gaps and challenges within the healthcare system since ASHA workers are community based healthcare workers who reside in the same area they serve. This close proximity enables them to develop strong relationships with community members, gaining insights into their health concerns, cultural beliefs, and socio-economic factors influencing healthcare access and utilisation. Therefore, ASHAs will have a better understanding of the nuances specific to rural settings. With a deep understanding of the unique healthcare challenges arising from geographical, infrastructural, or socio-cultural factors, ASHA workers can help tailor interventions accordingly. Through door-to-door visits and one-on-one interactions, they gather firsthand information on health-related issues, and healthcare disparities, capturing the intricacies of rural health. This personalised approach enables them to gain valuable insights into the challenges faced by individuals and the community as a whole. By actively engaging with the community, ASHA workers can foster a more inclusive society that supports individuals with these conditions and their families. By supporting the detection of these conditions and advocating for improved healthcare services, ASHA workers contribute to the ongoing improvement of the healthcare system's efficiency and effectiveness. Their insights and feedback can help shape policies and interventions better to address the needs of individuals with the 3Ds and enhance overall healthcare service delivery. However, ASHA workers face several challenges in their role of aiding RBSK and therefore lagged in providing support to parents and children who are affected by 3Ds. For example, limited access to comprehensive training programs and specialised resources hinders their ability to acquire the necessary knowledge and skills for accurate detection. This report will address their perspective and feedback in the later sections.

## **Workshop Overview**

The primary focus of the workshop was to examine the firsthand experiences of ASHAs and advocate for the inclusion of their grassroots experiences in policy design to enhance health outcomes. This workshop was to delve into the challenges encountered in child and maternal healthcare programs, with a specific focus on the Rashtriya Bal Swasthya Karyakram (RBSK). The workshop primarily focused on three of these domains, namely: Defects at birth, Diseases, and Developmental delays. The rationale behind this selective focus was the workshop's emphasis on rare diseases. Addressing deficiencies in addition to the three aforementioned domains would have overshadowed the workshop's main objective, as India, being a developing country, faces a significant number of children suffering from various types of deficiencies during their childhood. The objective of the workshop was to facilitate knowledge exchange and raise awareness regarding rare diseases that can be identified through the 3Ds: Birth Defects, Developmental delays, and Diseases. Furthermore, the workshop aimed to gain a comprehensive understanding of the challenges encountered by the ASHAs in the field when assessing and reporting such cases. The workshop was held at Primary Health Centre at Ghumabali, from 9 am to 2 pm, on the 3rd March 2023, and was attended by 28 ASHA workers. The workshop was conducted in the local language, Kannada, to ensure that the ASHA workers could easily understand the information provided.

During the first half of the workshop, health expert from CTRITH, Dr Tanya Seshadri, conducted

sessions to educate the ASHA workers about 3Ds. The sessions aimed to provide information about the various birth defects, developmental delays, and diseases that can occur in newborns. The experts also provided the ASHA workers with guidelines and protocols for identifying these conditions. The second half of the workshop was dedicated to encouraging ASHA workers to share their lived experiences. The workers shared their ground-level experiences, challenges, and feedback on the RBSK program. This session was critical as it helped the experts understand the ground-level challenges faced by the ASHA workers. The last session of the workshop was roleplay activity in which ASHA volunteers roleplayed senior public health officials, themselves, and patients and their families. They were given five different scenarios under which they had to communicate the issue to the senior officials and help families find solutions, while providing policymakers essential information. The agenda of the workshop is given below:

Table 1: Workshop agenda

Time (IST)	Session	Session detail
9:00 -10:00		Breakfast & Registration
10:00 -10:10	I	-Introduction to workshop - Acknowledging the role of ASHA workers, their importance in providing health services to rural and remote areas, and why and how they should be involved in grassroots science advice for local policy making.
10:10-10:30	II	-Introduction to birth defects, development delay and disabilities -Importance of early screening for birth defects, developmental delay and disability - Sensitising them about existing RBSK programs that mandate ASHAs to collect data for the 3Ds
10:30-11:30	III	Breakout session: small group discussion on identifying barriers and challenges that ASHA face (5 groups)
11:30-12:00	IV	Joint group discussion with ASHA on identifying common barriers and facilitators
12:00-12:45	V	Role play activity to identify effective communication channels between ASHA and senior public health officers
12:45-13:00		Concluding Remarks & Certificate distribution

The feedback and suggestions received from the workers can be used to improve the program's implementation and make it more effective.

# Feedback from ASHA workers

All the ASHA workers who attended the workshop have come across cases of birth defects, developmental delays, or disabilities, and their first step is to convince the family of the importance of seeking medical help. However, they highlighted the difficulty in persuading families to accept that their child may have special needs. The lack of visible illness in some cases, such as developmental delays, further complicates the process. ASHA workers mentioned referring such cases to the primary health care centre or taluk hospital for further evaluation and support.

Some of the concerns of ASHA workers are:-

## **Follow-up and Support:**

ASHA workers expressed varying levels of follow-up with the cases they reported. Some mentioned actively following up with the families, while others cited challenges in doing so due to lack of time, lack of support, and overburdened workloads. Repetitive visits sometimes led to a lack of cooperation from families who believed their child would eventually grow out of the condition. However, some ASHA workers mentioned involving higher authorities to ensure continued support and monitoring.

## **Difficulties in Assessing and Reporting:**

The ASHA workers encountered several difficulties in assessing and reporting cases of birth defects, developmental delays, and disabilities. One major challenge was the reluctance of families to accept that their children may have differences or special needs. Lack of support and a communication system from lower-level authorities to higher-level authorities were also highlighted as obstacles. Additionally, the ASHA workers felt burdened by their workload, which made it difficult to dedicate sufficient time for following up on these cases.

## **Addressing the Difficulties and Future Recommendations:**

To address these difficulties, ASHA workers emphasised the need for early screening during pregnancy to detect any birth defects, giving parents the option of abortion if they choose. They stressed the importance of raising awareness among parents and providing education about these conditions. Some ASHA workers referred cases to trained healthcare professionals such as General Nursing and Midwifery and Medical Officers. ASHA workers also advocated for immediate treatment options and improved communication mechanisms for referring and treating these cases.

## **Training Programs:**

ASHA workers mentioned attending training sessions conducted for health programs such as RBSK, Home Based Newborn Care, and Home Based Young Child Care. These training programs were deemed helpful in improving their understanding of these conditions and guiding them on appropriate actions to be taken when identifying such cases.

## **Communication Challenges:**

ASHA workers acknowledged that while communicating about appropriate care for patients with birth defects, developmental delays, or disabilities can be relatively easier in some cases, it is often a challenging and labor-intensive task. The lack of a well-established communication system, both within the healthcare system and between ASHA workers and families, was identified as a major obstacle. Overburdened workloads and financial issues further compoun-

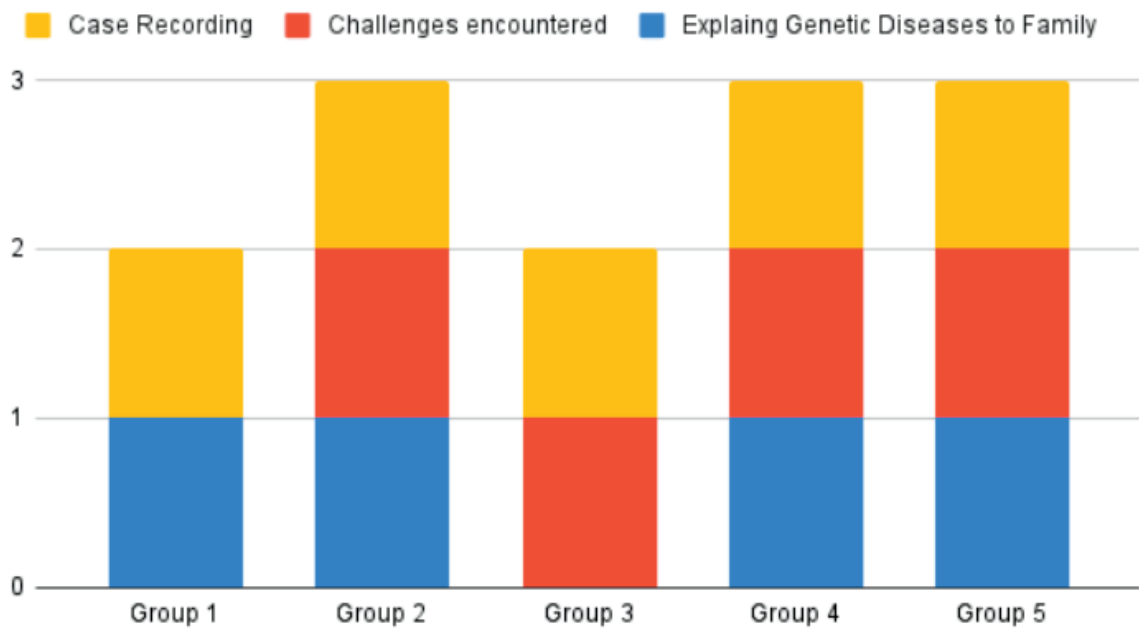


-ded these communication challenges.

The feedback from the workshop revealed that ASHA workers face numerous challenges in identifying, reporting, and providing appropriate care for cases of birth defects, developmental delays, and disabilities. Recommendations included early screening, raising awareness, improved communication mechanisms, and support systems for families. The ASHA workers expressed the importance of training programs that equip them with the knowledge and skills necessary for addressing these conditions effectively.

The bar graph below represents five different groups in which workshop participants, ASHAs, were randomly segregated for the exercise and their cumulative/aggregate experiences and responses were documented. The graph indicates that all five groups record cases related to genetic disorders when they first encounter any cases related to 3Ds. This implies that each group acknowledges the importance of documenting and keeping a record of such cases. However, when it comes to explaining genetic disorders to families during home visits, there is a variation among the groups. Four out of the five groups reported that they need to provide explanations to families about genetic disorders. This suggests that there might be a lack of understanding or awareness among the families regarding genetic disorders. Additionally, the graph shows that four out of the five groups face challenges while recording and encountering these cases.

### ASHAs Knowledge About Genetic Disorders

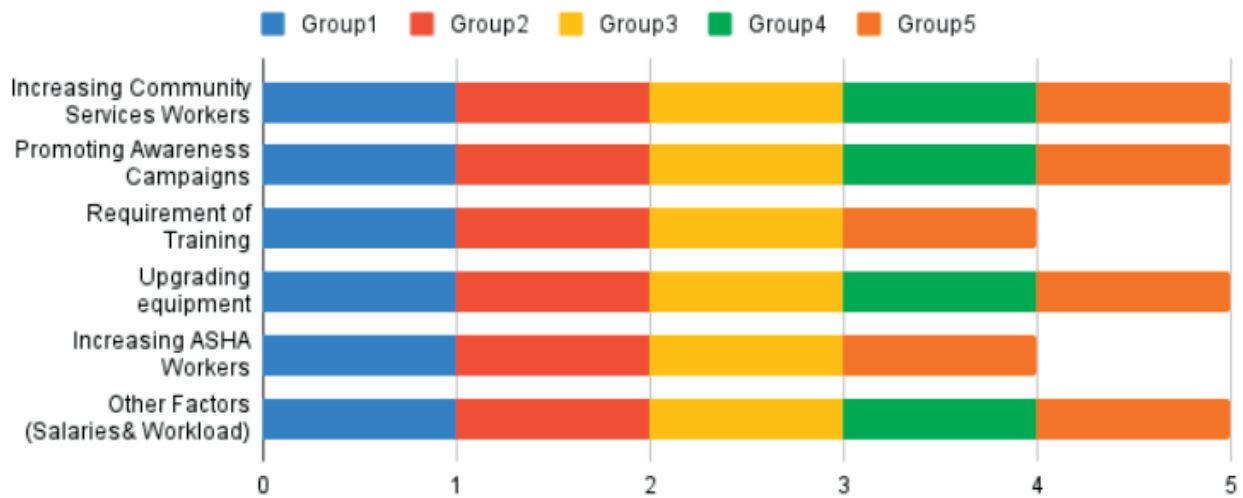


**Fig. 1:** ASHAs experience when they first recorded a genetic case. The workshop attendees were segregated into 5 groups randomly for this exercise and responses of each group were recorded.

The second bar graph presents the suggestions and feedback provided by ASHA workers. It reveals the perspective of five groups of ASHAs workers regarding measures that can enhance their effectiveness in addressing the 3Ds in the rural areas. Remarkably, all the five groups of ASHAs advocate for the allocation of additional services and workers in the community. The second common viewpoint expressed by all five groups is the potential efficacy of awareness campaigns in improving the understanding and recognition of 3Ds within the community. Furthermore, the bar graph demonstrates that equipping ASHA workers with upgraded kits is widely regarded as beneficial by all groups. Four out of the five groups of ASHA workers expressed

a desire for more training. Lastly, the graph reveals that four out of the five groups of ASHA workers believe that expanding the number of individuals in the ASHA workforce would be helpful.

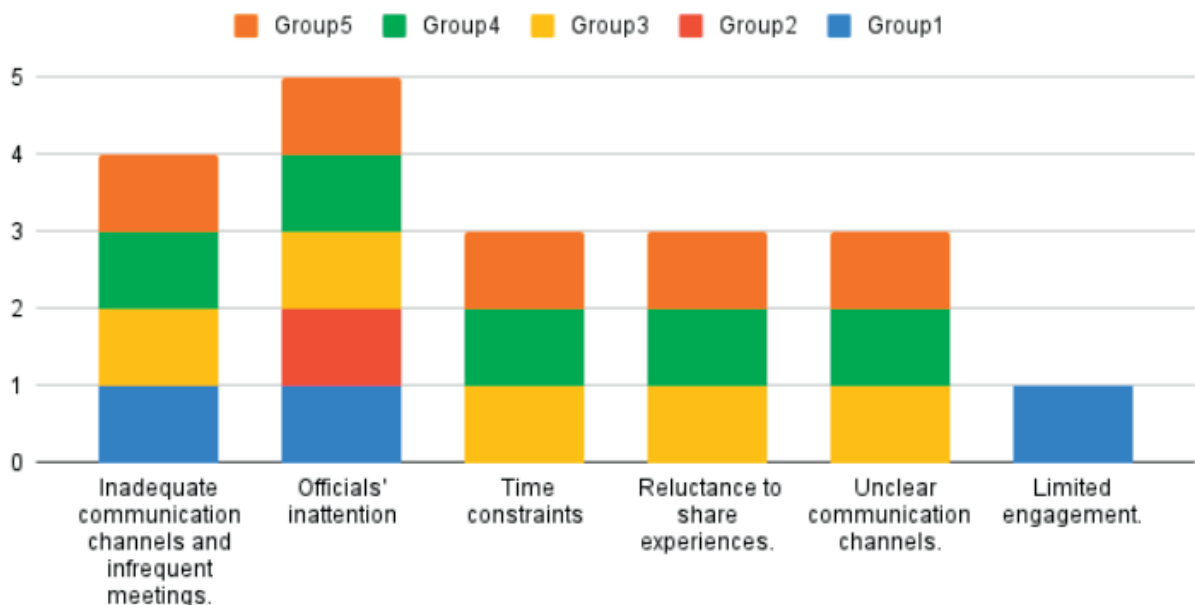
### ASHAs Suggestion for Improvement



**Fig 2:** Suggestions and feedback by ASHA workers on what measures can enhance their effectiveness in addressing the 3Ds in the rural areas. The workshop attendees were segregated into 5 groups randomly for this exercise and responses of each group were recorded.

The bar graph below illustrates the challenges faced by ASHA workers in effectively communicating about the reporting of cases related to 3Ds. The workshop attendees were randomly segregated into five groups for this exercise. These groups share common concerns, with two prominent issues emerging across all groups: the perceived inattention of officials and the inadequacy of communication channels, along with infrequent meetings.

### Communication Challenges



**Fig. 3:** Challenges faced by ASHA workers in effectively communicating about the reporting of cases related to 3Ds. The workshop attendees were segregated into 5 groups randomly for this exercise and responses of each group were recorded.



All the five groups of ASHA workers express about the perceived inattention of the officials, and the second major hurdle reported by the ASHA workers is the inadequacy of communication channels, coupled with infrequent meetings. This suggests that the existing mechanisms for communication and coordination between the ASHA workers and relevant stakeholders are insufficient. Furthermore, three out of the five groups of ASHA workers mention time constraints and reluctance to share experiences as additional challenges they encounter in their communication efforts. Additionally, the ASHA workers express concerns about the lack of clarity regarding whom to approach for communication purposes, indicating unclear communication channels. This issue highlights the need for well-defined and accessible pathways of communication.

## Discussion and Conclusion

The experiences and knowledge shared by ASHA workers in dealing with cases of birth defects, developmental delays, and disabilities can provide valuable insights for policy reforms.

**Awareness and Education:** Policy reforms should prioritise raising awareness among families and communities about birth defects, developmental delays, and disabilities. This can be done through targeted education programs, campaigns, and information dissemination to ensure that families understand the importance of early intervention and appropriate care.

**Enhancing Coordination Mechanisms:** Policy reforms should prioritise the development of robust communication and coordination mechanisms between ASHA workers and higher-level healthcare authorities. This can ensure that cases are appropriately reported, assessed, and referred for further evaluation and support.

**Workload and Support:** Policies should address the issue of overburdened workloads faced by ASHA workers. This can be achieved by providing adequate support, including training programs, supervision, and additional staffing, to ensure that ASHA workers have sufficient time and resources to effectively follow up on cases and provide the necessary support to families.

**Integration of ASHA Workers' Experiences:** Policy reforms should actively involve ASHA workers in the policy-making process. Their experiences and knowledge can contribute to the development of effective policies, guidelines, and strategies for addressing birth defects, developmental delays, and disabilities. Regular consultations, feedback mechanisms, and platforms for sharing experiences can facilitate the integration of their insights into policy formulation and implementation. Active involvement of these frontline healthcare workers in the policy-making process holds significant potential for the development of effective policies, guidelines, and strategies aimed at addressing the challenges associated with birth defects, developmental delays, and disabilities. The valuable experiences and knowledge accumulated by ASHA workers through their direct engagement with communities can offer invaluable insights for shaping policies that are grounded in the realities of the field. To ensure meaningful integration, it is crucial to establish regular consultations, feedback mechanisms, and platforms dedicated to the exchange of experiences. These avenues enable ASHA workers to share their on-the-ground encounters, challenges, and successes, thereby contributing to the formulation and implementation of policies that are better aligned with the needs and aspirations of the communities they serve. Furthermore, the inclusion of ASHA workers' perspectives in policy formulation can help bridge the gap between theoretical policy frameworks and practical impl-

-ementation. Their unique understanding of the local context, cultural nuances, and community dynamics enriches policy deliberations, ensuring that the policies developed are contextually appropriate, feasible, and sustainable. feedback can inform adaptive policy adjustments, ensuring that policies remain responsive to the evolving needs and challenges on the ground.

The experiences shared by ASHA workers during the workshop provide valuable grassroots-level insights that can significantly contribute to policy formation regarding birth defects, developmental delays, and disabilities. These frontline healthcare workers have firsthand experience and understanding of the challenges faced by families and communities in dealing with these issues. By incorporating their feedback, policymakers can gain a more comprehensive understanding of the ground realities and formulate effective strategies to address the identified challenges. The ASHA workers highlighted the need for early screening, awareness campaigns, improved communication systems, and support mechanisms for families. This information can guide policymakers in designing targeted interventions and policies that prioritize early detection, timely intervention, and comprehensive support for affected individuals and their families. It also underscores the importance of providing adequate training and resources to ASHA workers, empowering them to effectively identify, report, and address cases in their communities. Incorporating grassroots-level data in policy formation ensures that the policies are grounded in the realities and needs of the communities they aim to serve. It helps bridge the gap between policy formulation and implementation, as it takes into account the challenges and resources available at the local level. By actively involving ASHA workers and other frontline healthcare providers in the policy-making process, policymakers can harness their expertise and insights to develop more targeted, evidence-based, and impactful policies. The inclusion of grassroots-level data from ASHA workers in policy formation can lead to more effective, responsive, and sustainable approaches in addressing 3Ds. It enables policies to be better aligned with the needs and realities of the communities, ultimately improving the quality of care and support provided to individuals and families affected by these conditions.

# Financial Report

<b>Debit Heads</b>	<b>Amount in INR (₹)</b>	<b>Amount in Euro ( ₹1 = €87.3)</b>
Honorarium to Workshop Resource Persons	37000	424
Printing (banner and certificates)	2388	27
Workshop kit for participants	13682	157
Press Release	3000	34
Travel and accommodation	7186	82
Travel Allowance for workshop participants	6000	69
Venue catering	11910	136
Report design, printing and publication	5000	57
Miscellaneous	1114	13
Amount Spend	87280	1000
Total Amount Received	87280	1000
Balance	0	0

# Photo Gallery



Image 1: Workshop banner



Image 2-7: During the event