

## Global Priorities and Local Realities:

Exploring what happens to children identified with Acute Flaccid  
Paralysis under the Pulse Polio Programme in Uttar Pradesh, India

By

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A dissertation submitted to the University of Liverpool,  
Liverpool School of Tropical Medicine, International Health Research Group,  
in partial fulfilment of the requirements for the award of  
the Master of International Public Health (MIPH) degree

July 2008

## Executive summary

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### Background

Poliomyelitis, or polio, is a paralytic disease of virus aetiology in children transmitted faecal-orally. It causes acute flaccid paralysis (AFP) in less than 1%, but once this occurs, can lead to lifelong paralysis, or residual paralysis. Prevention by vaccines is essential because there is no curative treatment. Those infected, irrespective of severity, shed the virus in their stools for weeks, potentially infecting others.

In 1988, the Global Polio Eradication Initiatives was launched to eradicate polio from the world, and much effort was put in. Now, there are only four countries endemic in polio: India, Nigeria, Pakistan, and Afghanistan. Among the four, India is in the worst situation, in spite of its intensive Pulse Polio Programme. Under this programme, polio vaccines are given to children under 5 years-old almost every month, house-to-house, and children with polio are detected through its surveillance system. There were 873 polio cases, and over 40,000 non-polio AFP cases reported in 2007.

In this study, characteristics of children identified with AFP are explored along with their experiences with respect to their difficulties, health needs, and health services provided. Healthcare providers and key informants from the community were approached to explore around the same issues. The results were used to devise strategic options for improvement of the programme and to enhance quality of life of these children.

### Study methods

Families of children with polio (17), with non-polio AFP (9), and with residual paralysis (18), healthcare providers (38), and key informants from the community (15) were interviewed. The study gained participation from most families of children with polio diagnosed within previous three years in six residential blocks in the District of Muzaffarnagar in Uttar Pradesh. Otherwise, it was purposive sampling. The study also conducted 7 focus group discussions with mothers of children under 5 years-old to acquire background information of the area. Direct observations, secondary data collection and review, field diary, and descriptive quantitative analysis were used as additional methods.

Interviewed data were recorded, transcribed, and translated from Hindi into English. Framework approach was used to identify themes emerging from the data. Informed consent was obtained from all participants, and confidentiality was maintained at all times.

## Main findings

Children with AFP were generally living in poverty, in crowded conditions with poor sanitation, and their parents were often illiterate. All children received polio vaccines from house-to-house activities of the Pulse Polio Programme, but very few received them from routine immunization.

Public healthcare services of the area were poor in quality, and therefore, many people preferred private practices. Government hospitals lacked medicines, manpower, and adequate facilities. The workload of the Pulse Polio Programme affected other healthcare services including routine immunization. The programme impacted on the community by shaping their belief and behaviour, especially for the poorly educated, that the 'polio drops' were for every disease and they were getting protection against all diseases at their homes.

Most families of children with AFP received little healthcare, except for stool tests and occasional visits by doctors to their houses. Their visits to private hospitals incurred much financial burden, and were distressed that their children got polio despite their 'polio drops'. In contrast, healthcare providers considered they were providing a good service to these children.

The needs of these children were medical support including medicines and rehabilitations, and transportation facilities and mobility aids which aid access to education. Most were not having these needs fulfilled. Some existing government policies and social welfare services were available to them, but there was little awareness of these among the families or healthcare providers.

## Conclusions

This study was the first to focus on the experiences of children identified with AFP under the surveillance of the programme. Their poverty made them vulnerable not just to poliovirus but also within the social world, and many were not receiving adequate healthcare and support. To improve the programme, there needs to be more attention paid to these children, to know who they are, and ensure better provision of healthcare. This should also benefit the move toward global polio eradication by bringing confidence among the community that 'Yes, polio is being cured'.

### Word count

Executive summary: 674

Total word count: 17,040

## Acknowledgements

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There is uncountable number of people I would like to convey my thanks to.

First of all, many thanks to Katharine, my tutor, who helped me throughout the course, and especially with this project. I could not have presented this research as the way it is now without her ungrudging support, and I am just so grateful for her patience and all her helpful advices.

Special thanks to people of Muzaffarnagar who welcomed me and made my stay there comfortable, despite of difficulties at times. I am grateful for Shri Subhash Sharma, the District Magistrate of Muzaffarnagar, who kindly showed interest to my study and facilitated my field work to a large extent. I could not thank enough for all the members of Astitwa who were always there to support me, and also shared their precious experiences which encouraged me how strong a person can be.

I appreciate all the advices I got from Dr. Abhijit Das, my client who is also the creator of this interesting theme for my dissertation project, and also from Dr. Amitrajit Saha, Dr. Onkar Mittal, and Mr. Vasistha Bhardwaj. Thank you to Jayeeta for all your support as a project manger and also as a friend during my stay in India, and I must thank my co-researchers, Nitesh and Melissa, for all their hard work in this project. I also have to thank Sunita who agreed to do so many translations in so short notice.

Most importantly, many thanks to all who participated in this research study.

I appreciate all the support I received from everyone that made my achievement in this course possible: from St. Luke's International Hospital back in my home country, in Japan, all the staff in Liverpool School of Tropical Medicine, and still many many others that I can not possibly name all.

Lastly, I thank my parents who have enabled me to reach this stage and always have been there for me with their infinite love.

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## Abbreviations

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AFP	Acute flaccid paralysis
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
CDC	Centers for Disease Control and Prevention
CHC	Community Health Centre
DIO	District Immunization Officer
FGD	Focus group discussion
GPEI	Global Polio Eradication Initiatives
GoI-CBHI	Government of India, Central Bureau of Health Intelligence
GoI-MoFW	Government of India, Ministry of Family Welfare
GoI-MoF	Government of India, Ministry of Finance
GoI-MoH&FW	Government of India, Ministry of Health & Family Welfare
GoI-MoSJ&E	Government of India, Ministry of Social Justice & Empowerment
GoI-WHO	Government of India-WHO Collaboration
GoMuz	Government of Muzaffarnagar
GoUP	Government of Uttar Pradesh
GoUP-FW	Government of Uttar Pradesh, Family Welfare
IPV	Intravenous polio vaccine
m.	months
M.B.B.S.	Bachelor of Medicine and Surgery
NPSP	National Polio Surveillance Project
OPV	Oral polio vaccine
OPD	Outpatient department
PHC	Primary Health Centre
RI	Routine immunization
Rs.	Rupees
SIAs	Supplementary immunization activities
WHO	World Health Organization
WPV	Wild poliovirus
yr.	years

# Chapter 1: Introduction

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## Introduction

This chapter begins by introducing background information to the worldwide movement toward eradication of polio and situation in India, followed by description of the study setting; this is to help set the scene for the study. The last section explains the purpose for this research study.

## 1.1 Background to the study

### 1.1.1 Poliomyelitis

Poliomyelitis, often referred to as polio, is a highly infectious disease caused by poliovirus. It spreads from person to person mostly affecting children under 3 years old through faecal-oral route. In most cases, infections are asymptomatic causing no harm. Less than 1% who are severely infected may lead to lifelong paralysis (Atkinson, 2007). However, irrespective of severity, all infected individuals shed the virus in their stool for weeks and can infect others. There is no specific treatment for polio, and thus, prevention by vaccines is absolutely essential.

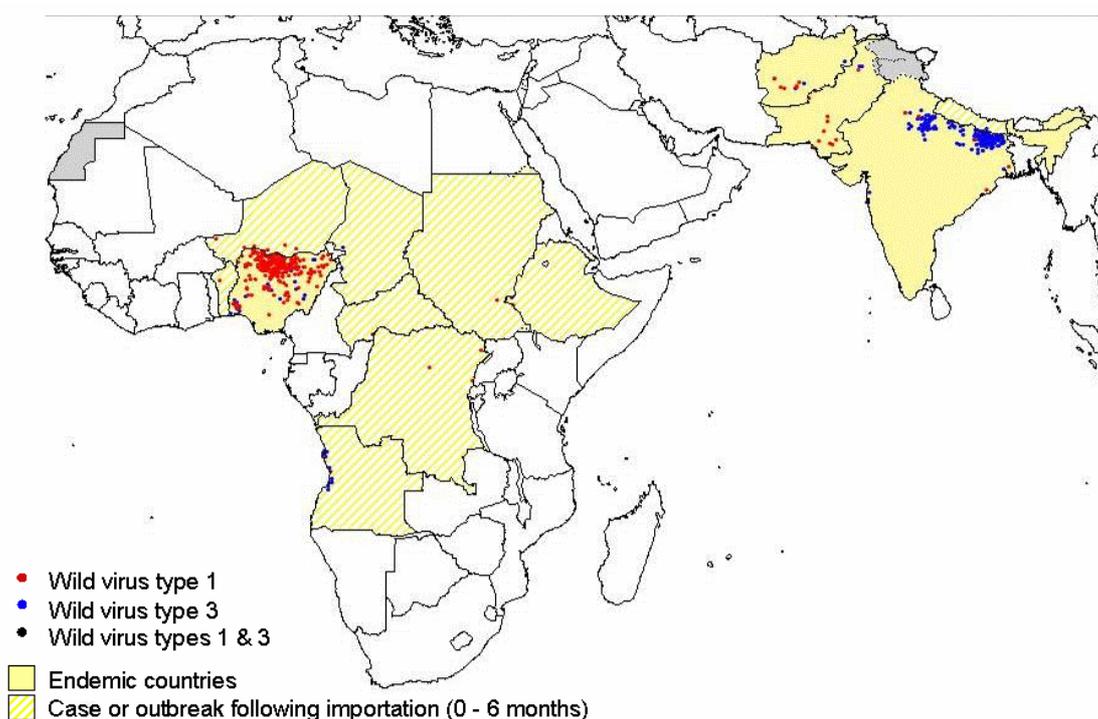
### 1.1.2 Global situation and India

Since the launch of the Global Polio Eradication Initiative (GPEI) in 1988, 'the largest international public health effort to date', many countries and international organizations have worked toward eradication of polio from the world (WHO, 2003; pp.6). Due to massive effort and huge investment of over \$5 billion, now only four countries are endemic in this disease: India, Nigeria, Pakistan, and Afghanistan (GPEI, 2008a) (Figure 1). Among the four, India is having most cases as of now, also with some outbreaks from time to time (Table 1). Nevertheless, polio has been eliminated from many places in India; it is just the two states, Uttar Pradesh and Bihar, where they are still having intense local transmission and remaining to be the last pockets for the poliovirus.

Table 1: Wild poliovirus confirmed cases 2000-2007 (Source: GPEI, 2008b)

Country	2000	2001	2002	2003	2004	2005	2006	2007
India	265	268	1600	225	134	66	676	866
Nigeria	28	56	202	355	782	830	1122	286
Afghanistan	27	11	10	8	4	9	31	17
Pakistan	199	119	90	103	53	28	40	32
World	719	483	1918	784	1255	1979	1997	1308

Figure 1: Map of polio cases worldwide in 2008 (Source: GPEI, 2008b)



### 1.1.3 Polio and Uttar Pradesh

Uttar Pradesh, situated in the north-western part of the country, is often characterized by its high population density and severe poverty. In the 2001 census, the latest data available, Uttar Pradesh's population was the highest in India, accounting for 16.2% of the country's 1.1 billion population (Gol-CBHI, 2008). Population density was 690 persons per sq. km. when the national average was 325 (Gol-CBHI, 2008). Poverty has decreased over the past few decades, but it is still estimated 31.2% of its population is living below poverty line (GUP, 2003). Per capita income of Uttar Pradesh was Rs. 9,753<sup>ξ</sup>, 45.7% lower than the national level (GUP, 2003). High population density and poverty lead to poor sanitation and poor health status, and these factors all together are said to be making the place a good 'hiding place' for poliovirus (Roberts, 2004). Selected health status outcomes comparing Uttar Pradesh and other states are given in APPENDIX 1.

The number of polio cases declined to around 250 cases per year in India in early 2000, attributed to the on-going immunization scheme under GPEI (WHO, 2008a). However in 2002, poliovirus once again spread throughout the country and to the world, re-infecting 27 polio-free countries (CDC, 2002). All together 1,600 cases were reported nationwide, and out of these, 1,218 cases occurred in Uttar Pradesh (CDC, 2002; WHO, 2008a). Most cases were from wild poliovirus type 1 (WPV1), the most virulent type

<sup>ξ</sup> Rs. = Rupees: Indian currencies, \$1=Rs. 42

which circulates wildly and accounts for international spreads (GoI-WHO, 2008). Being the epicenter for this fatal virus, reducing polio cases in Uttar Pradesh is regarded as fundamental in achieving the global polio eradication.

#### **1.1.4 Preventing polio**

There are several vaccines for polio, and other countries have used them effectively to eliminate the disease from their countries.

Currently, India is running the Pulse Polio Programme for the same aim. The programme was established in 1995 as part of GPEI, and two main strategies have been used to reduce polio cases. One strategy is known as the National Immunization Days (NIDs) where oral polio vaccines (OPV) are administered to as many children in a short period of time, along with taking them through routine immunization schedules. Sub-national Immunization Days (SNIDs) are held for smaller scale activities in areas identified as 'high risk areas' in addition to NIDs. Another important aspect of the programme is the Surveillance for Acute Flaccid Paralysis (AFP). AFP is a type of paralytic syndrome where one's arms and/or legs suddenly become weak. Poliomyelitis is one among several other diseases which causes this symptom. Surveillance utilizes this characteristic of poliomyelitis in order to detect new polio cases. When case is detected, outbreak response immunization is organized in locality of the case, and also unrecognized cases are searched from house-to-house.

#### **1.1.5 Current situation and concerns**

In recent years in Uttar Pradesh, it is estimated by the Indian Academy of Pediatrics Polio Eradication Committee (IAP-PEC) that the coverage for OPV is near 100% with 4-10 doses--average 15 doses per child since 2003-- reflecting the intensified Pulse Polio Immunization programme (IAP-PEC, 2007). They also presume the world's most vaccinated children under 5 years old with OPV are in Uttar Pradesh and Bihar, whereas for most of other vaccine preventable diseases, coverage are below 50% (IAP-PEC, 2007; CDC, 2007; etc.).

As for AFP Surveillance, 41,529 cases were reported in India in 2007 which is a huge increase by several folds compared to few years back. In 2003, it was 8,505 (WHO, 2008a). Detecting every case of AFP, even with mere paralysis, is said to be accounted for this increase; however, some are showing concerns to this high increase (Sathymala, 2005; Mittal, 2007; Neogi, 2006; etc.).

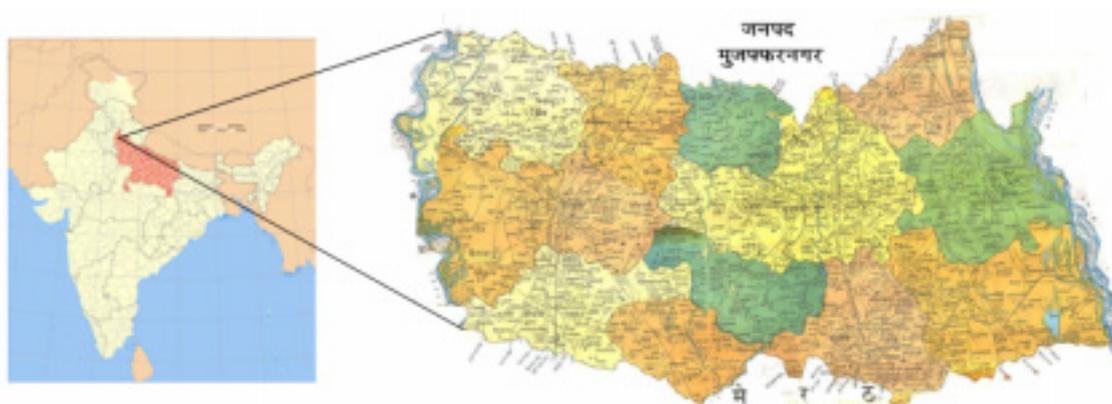
Another issue has been currently brought up regarding newly reported polio cases. It is now known that many of these children have been taking the vaccines, sometimes more than several doses, but still are affected by polio (Arora, 2007; IAP-PEC, 2008; etc.).

### 1.1.6 Healthcare for children identified with Acute Flaccid Paralysis

Regardless of high number of children with AFP, little is known what kind of healthcare they are receiving; if they are getting any treatments, care, and support after identification. Even though there is no definite treatment for polio, several measures can be taken to ease their symptoms including supportive and symptomatic medicines, physiotherapy, and mobility aids. Likewise, there are treatments and care for other diseases that cause AFP. However, information was not available for this area.

## 1.2 Study setting

The study was conducted in Muzaffarnagar, one district in western Uttar Pradesh where transmission of indigenous wild poliovirus is still occurring along with its neighbouring districts. The district is situated in-between the two great rivers of Ganga and Yamuna, giving the place fertile plains for agriculture, especially for its famous production of sugar (Figure 2). The district is highly populated with total population of 4.06 million, which 70% are estimated to be engaged in agriculture (GoMuz, 2008). There are many children in the district; 22% of the population are children below 5 years old (e.g., target population for the Pulse Polio Programme) and its birth rate is 32 per 1,000 people (GoMuz, 2008). This figure for birth rate is much higher compared to the national average of 25, and in fact, is one of the highest in India (GoI-CBHI, 2008). Infant mortality rate is 72 per 1,000 live births, which again is high having the national average as 57 (GoMuz, 2008; WHO, 2008b). Furthermore, there is much diversity to its people's religious and social backgrounds. There were 2.1 million Hindus and 1.4 million Muslims as of 2001 along with other minorities, but each of them is again divided into numerous castes within (GUP, 2003).



**Figure 2: Map of India and Muzaffarnagar** (Source: *Britanica Concise Encyclopedia, 2008; GoMuz, 2008*)

\*Red area in the Indian map is showing the State of Uttar Pradesh.

\*\* Different colours are showing different blocks in the district in the map of Muzaffarnagar.

The district is comprised of 5 *tehsils*<sup>ξ</sup>, and 14 blocks, and they are further divided into 1,025 villages which covers 893 inhabited villages (GoMuz, 2008). Government health facilities try to cover all these by having hierarchy in the system, namely there are one District Hospital, 14 Community Health Centres (CHC), 68 Primary Health Centres (PHC), and 368 Sub-centres in the district of Muzaffarnagar. In this study, six blocks were visited for data collection.

### **1.3 Purpose of the study**

While many are saved from polio by having OPV, it is starting to become clearer some children are still being affected even though they have taken them many times, sometimes as many as ten doses or more (Arora, 2007). Many hypotheses have been made to why this is happening, why OPV were not effective in these children in a scientific level. However, there have not been many insights into this question more from the point of view from the communities and the frontline healthcare providers. Also, there was little information available about what happens to children who were identified with AFP under this system, what were their experiences afterwards. The same was with the healthcare providers, and little was known around what were their experiences and perceptions looking after children with AFP.

Therefore, the purpose of this study is to answer the following questions:

- ✓ What are the characteristics of children who are getting affected with polio? Have they been taking polio vaccine?
- ✓ What are the experiences and perceptions of the families of children with AFP around the disease and healthcare services they were provided/ not provided?
- ✓ What are the experiences and perceptions of the healthcare providers around Pulse Polio Programme, AFP Surveillance, and AFP cases?
- ✓ What are the gaps between the experiences and perceptions of these families and the healthcare providers?

This study was done in collaborations with the Centre for Health and Social Justice (CHSJ), an organization based in New Delhi which aims to promote human development and equality with specific references to the field of health in India. CHSJ uses research as one of its key strategies to improve health policy and programme delivery for this aim. Thus, this research will be used to assist them in making advocacy for the children with AFP.

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<sup>ξ</sup> An administrative unit consisting of several blocks; hierarchically subordinate to a district

## Chapter 2: Literature Review

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### Introduction

This chapter is devoted to introducing background information for polio and its current situation in Uttar Pradesh, India. There are a number of important characteristics of polio that should be understood before proceeding on with the main theme, and these are reviewed in the first section. The second section describes the content of the Pulse Polio Programme followed by some current situation and concerns. Similar researches conducted in the past are introduced in the next section, and finally rationales for this study will be given.

### 2.1 Search strategy

Sources used for searching relevant literatures are as follows:

- ✓ Electronic databases: Pubmed, Blackwell Synergy, Science Direct, JSTOR, Eldis
- ✓ Online journal articles: Lancet, Science, Nature, Indian Journal of Paediatrics Medicine, Indian Journal of Medical Research
- ✓ Websites: WHO, NPSP, CDC, UNICEF, Global Polio Eradication Initiative
- ✓ University of Liverpool libraries
- ✓ Unpublished literatures from relevant organizations and individuals

### 2.2 Clinical aspects of polio

#### 2.2.1 Cause and epidemiology

Poliovirus is a member of *Enterovirus*, a group of virus which are transient inhabitants of the gastrointestinal tract. There are three serotypes to wild poliovirus: type 1 (WPV1), 2 (WPV2), and 3 (WPV3). All types infect children and can lead them to paralysis. WPV1 is the most virulent causing more severe symptoms and more infectious compared to the other two (GoI-WHO, 2008). It is transmitted by faecal-oral route in most developing countries where sanitation is poor, whereas is mostly oral-pharyngeal for the more developed countries (PAHO, 2006). Humans are the only reservoir of poliovirus, and infection is passed on from person-to-person.

#### 2.2.2 Pathogenesis

Once poliovirus enters the body through the mouth, it multiplies itself in the pharynx and gastrointestinal tract. The virus subsequently enters the blood stream and spreads throughout the body. In small

percentages of cases, this may progress and the virus invades the motor neurons of the central nervous system resulting in manifestation of paralysis.

### 2.2.3 Clinical features

Incubation period for poliovirus differs across literatures, but is estimated to be around 7 to 10 days with a range of 4 to 40 days (Fauci, 2008; PAHO, 2006). There are various responses to poliovirus infection, and it is classified according to its severity of clinical symptoms.

Most poliovirus infections are asymptomatic, and approximately 4-8% consists of only minor symptoms (Atkinson, 2007; Fauci, 2008) (Table 2). These symptoms include mild fever, muscular pain, headache, nausea, and vomiting which cannot be distinguished from number of other illnesses. The symptoms disappear within a week's time. There are another 1-2% of cases where nonparalytic aseptic meningitis (symptoms of stiffness of the neck, back, and/or legs) occurs after some minor symptoms, but again this recovers after 2 to 10 days, giving complete recovery (Atkinson, 2007; Fauci, 2008).

Less than 1% progress to paralytic disease presenting acute flaccid paralysis (AFP) where the muscles become weak and floppy due to reduced muscle tone; most of the time, paralysis is asymmetrical in polio (Atkinson, 2007; Fauci, 2008). This type of poliovirus infection is classified as spinal, bulbar, or bulbospatial depending on the site of infection. Once paralytic symptoms occur, case-fatality rate increases to as high as 20%, and with bulbar involvement (region of the brain stem responsible for breathing, speaking, and swallowing), can be as high as 40% (PAHO, 2006) (Figure 3). Spinal polio is rarely fatal, but in half, patients are left with permanent paralysis, or 'residual paralysis', having the affected nerve cells completely destroyed (Cuccurullo, 2004).

Outcome	Proportion of cases
Asymptomatic	90-95%
Minor syndromes	4-8%
Non-paralytic aseptic meningitis	1-2%
Paralytic poliomyelitis	0.1-0.5%
- Spinal polio	79% of paralytic cases
- Bulbospatial polio	19% of paralytic cases
- Bulbar polio	2% of paralytic cases

Table 2: Outcomes of poliovirus infection (Atkinson, 2007)

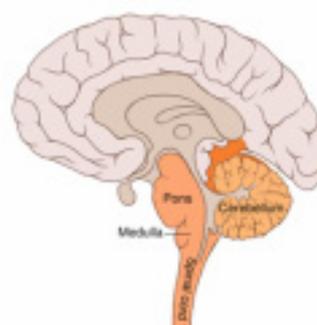


Figure 3: Bulbar paralysis is a destruction of one part of the central nervous system called the medulla, which can result in interruption of functions in breathing, swallowing, and speech.

(Image Source: Creative Commons Attribution)

#### 2.2.4 Laboratory diagnosis

Technical diagnosis of poliomyelitis is done in laboratories by isolating poliovirus from stool samples of a person with the disease.

#### 2.2.5 Differential diagnosis

Any kind of disease that causes AFP is considered as a differential diagnosis for poliomyelitis. Such diseases are: Guillain-Barre syndrome, transverse myelitis, and traumatic neuritis. The most prominent difference between poliomyelitis and others is that paralysis in polio is generally more severe and permanent, whilst with other causes, paralysis tends to resolve or improve within 60 days after the onset (PAHO, 2006).

#### 2.2.6 Treatment

Treatments for poliomyelitis are symptomatic and supportive, not curative. These include: antibiotic for secondary infections, analgesics for pain in the affected-limbs, moderate exercise, and a nutritious diet (Daniel, 1997). Rehabilitation including physiotherapy, braces, and corrective shoes are also important to sustain mobility (Fauci, 2008). Some cases with surgical indications undergo corrective surgeries including tendon-lengthening and nerve-grafting to improve function and stabilize the spine and the limb (Perry, 1995).

#### 2.2.7 Prevention through vaccines

Two types of vaccines are currently available for prevention of polio: oral polio vaccine (OPV) and inactivated polio vaccine (IPV). OPV uses live attenuated viruses and administered orally, whereas IPV uses inactivated virus and administered intramuscularly. OPV can be further divided into three types according to its target. One is trivalent OPV (tOPV) which targets all three serotypes of poliovirus. The other two are called monovalent OPV (mOPV) 1 and 3 and target only one serotype, either WPV1 or WPV3. (Photo 1)

There are several fundamental differences between OPV and IPV due to the origin of the two vaccines. Firstly, since OPV is made from live attenuated virus, it is highly heat-sensitive and requires careful handling, which is commonly known as maintaining 'cold-chain'. In contrast, IPV is made from dead virus which makes it more stable and easy to handle.



Photo 1: Oral polio vaccine or 'polio drops'

Secondly, because vaccine virus is still alive in OPV, sometimes it converts back into its virulent form causing paralysis in those who are administered the vaccine. This paralysis is called 'vaccine associated

paralytic poliomyelitis (VAPP)', and this is another unique characteristic of OPV which IPV does not have. The risk is said to be at an average 1 case of VAPP per 2.5 million doses of OPV, and is considered to be a serious adverse effect of the vaccine (Sutter, 2006). In fact, the only cause of poliomyelitis in industrialized countries nowadays is from vaccine virus (CDC, 2008). Oliveira (2000) investigated AFP cases in Brazil and found an 8.88 risk ratio of VAPP [95% CI: 4.37-18.03,  $p < 0.01$ ] when comparing children who received OPV between 4-40 days before the onset of paralysis and children who did not receive OPV within this period.

Thirdly, while seroconversion<sup>ξ</sup> for IPV is known to be close to 100%, the case is not the same for OPV. Further, seroconversion for each of the three polio strains varies. The percentages differ according to sources, but combining some figures together, the ranges are 55-89%, 92-95%, 65-83% respectively for WPV1, WPV2, and WPV3 after administration of three doses of OPV (Jaiswal, 2000; Paul, 2005; Hasan, 2004). The percentages went higher with more doses, but not as high as 100%. These figures imply that even with several doses of OPV, prevention of polio may never be perfected with OPV.

However, despite some of these disadvantages over IPV, there are also some claimed advantages in OPV. It is inexpensive, easy to administer, and has potential for herd immunity, and therefore is chosen to be administered to children in many countries (Roberts, 2004). Recommended routine schedule for polio vaccine may vary from country to country, but it is usually three doses of tOPV at four to eight week intervals starting at 6 weeks of age or 2 months. In endemic countries like India, extra dose at birth is recommended which makes it four doses in total (PAHO, 2006).

## **2.3 Global Polio Eradication Initiatives**

### **2.3.1 History**

After smallpox had been eradicated from the world in 1979, polio was chosen to be the next disease to be eradicated by the global powers. In 1988, the Global Polio Eradication Initiatives (GPEI) was launched with participation of national governments, World Health Organization (WHO), Rotary International, US Centres for Disease Control and Prevention (CDC), and UNICEF. Its goal is defined as follows (Gol-WHO, 2008):

- ✓ No cases of clinical poliomyelitis associated with wild poliovirus
- ✓ No wild poliovirus found worldwide despite intensive efforts to do so

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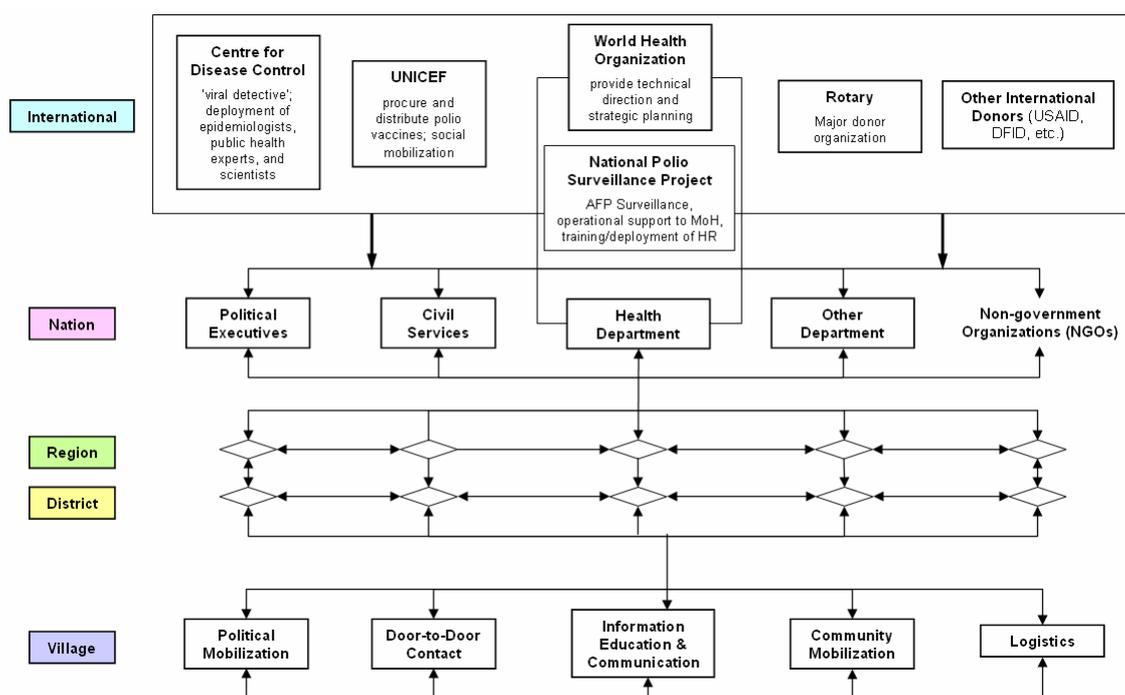
<sup>ξ</sup> seroconversion: state in which antibodies to microorganisms are developed successfully in the blood serum, or in another words protection against that microorganisms is successfully established inside the body

### 2.3.2 Polio eradication movements in India

OPV was first included in the national immunization schedule in 1978 as part of the Expanded Programme on Immunization, and then promoted to Universal Immunization Programme in 1985, in which polio vaccine was included in routine immunization along with other five diseases. By early 1990s, the coverage of polio vaccine was over 90%, and the number of reported cases had decreased from 28,757 in 1987 to 3,265 in 1995 (GoI-Family Welfare, 2008).

India became one of the signatory countries of the GPEI in 1988, but it was not until 1995 the Pulse Polio Programme was launched as part of the GPEI to intensify strategies to eradicate polio from India. National Polio Surveillance Programme (NPSP) was added to the Pulse Polio Programme in 1997 to serve as surveillance system to detect all cases of AFP, then investigate and diagnose polio. NPSP is a collaborative organization between the Government of India and the WHO. The below figure describes the key players of the programme (Figure 4).

Figure 4: Conceptual framework for key players of the Pulse Polio Programme



(Modified from: Bonu, 2004; Additional information from GPEI, 2008)

### 2.3.3 Pulse Polio Immunization Programme: Eradication strategies and quality

Main strategies to achieve polio eradication are defined as follows (Sutter, 2006; pp.203-204):

- ✓ Achieve and maintain the highest levels of routine immunization coverage with OPV
- ✓ Establish sensitive surveillance system to detect all cases of AFP
- ✓ Conduct Supplementary Immunization Activities (SIAs) (National Immunization Days (NIDs) or Sub-national Immunization Days (SNIDs)) with OPV
- ✓ Carry-out focused campaigns ('mop-up' campaigns) to eliminate the last foci of transmission

#### ◆ **Supplementary Immunization Activities**

Supplementary Immunization Activities (SIAs) include National Immunization Days (NIDs) and Sub-national Immunization Days (SNIDs). NIDs target all children less than 5 years of age, regardless of previous vaccination status, administering two drops of OPV, separated by 4-6 weeks. With SNIDs, they have the same target age group and operational approaches, but the campaigns are limited to sub-national levels. It is currently a one-week programme, starting on Sunday with a 'booth day' where fixed post is set up for mothers to come and have their children vaccinated; followed by 'house-to-house' rounds for rest of the week. In 'house-to-house' rounds, a team of vaccinators, comprised of frontline healthcare workers called ANMs (Auxiliary Nurse Midwives)<sup>¶</sup>, ASHAs<sup>θ</sup> (Accredited Social Health Activists), and Anganwadis<sup>ξ</sup> go house-to-house to give 'polio drops'<sup>ψ</sup> and try to reach each and every child of the community. (Photos 2-5)

The aim of SIAs is to 'flood' the community with OPV within short period of time because it is believed that effect of OPV increases considerably when administered in mass campaigns compared to routine immunization activities (GoI-WHO, 2008; Sutter, 2006; PAHO, 2006; etc.). However, evidence of this strategy is largely based on past experiences, especially with countries of Latin America where context was different from India and also strategies were different from those of present (e.g., 1 to 2-day activity whereas now is one week) (Sabin, 1984&1985; Bilous, 1997; Vadim, 1993). Nonetheless, three factors are given to be responsible for the enhanced effectiveness of OPV during campaign use: (1) increase in coverage even in areas with poor health systems; (2) enhanced effectiveness of OPV itself due to reduction of interference with other non-polio enteroviruses by overloading them; and (3) obtaining 'herd effect' of OPV, or in another words, obtaining secondary spread of vaccine virus and developing immunity in unvaccinated cohorts (Sutter, 2006).

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<sup>¶</sup>ANMs: health functionary closet to the community who not only looks after reproductive child health of the community but also takes care of other various things including family planning and preventive services (e.g., immunization)

<sup>θ</sup>ASHAs: a trained female voluntary Community Health Worker who support ANMs in immunization, safe institutional delivery, and other reproductive and health-related services; but also have important role in nutrition and sanitation

<sup>ξ</sup> Anganwadis: workers under the Integrated Child Development Scheme and they work for regular health check-up, immunization, health education, and non-formal pre-school education

<sup>ψ</sup> 'Polio drops' is the term generally used among community members to refer to polio vaccine.



Photo 2: ANM giving 'polio drops' during house-to-house rounds



Photo 3: A boy having his 'polio drops'



Photo 4: Child's little finger marked, a mark shows he has taken the 'polio drops'

Photo 5: Anganwadi checking off her list of children after giving 'polio drops'



#### ◆ AFP Surveillance

The aim of AFP Surveillance is to detect all cases of WPV through identification of AFP. The surveillance involves reporting of AFP suspected cases, and thereby testing stool specimen for WPV in specialized laboratories for diagnosis. Also, suspected children are followed-up to see if they will develop residual paralysis after 60 days of onset. Other main features of the system are listed below (Gol-WHO, 2008):

- ✓ Criteria for identification: (1) Manifestation of AFP, (2) Children younger than 15 years old
- ✓ Guideline for stool testing: (1) Two stool samples 24h apart and within 14 days of onset of paralysis, (2) Samples stored and transported to the nearest specialized laboratory maintaining below 8 °C by packaging in ice-filled container

- ✓ To avoid missing cases of paralytic poliomyelitis, the prevalence of non-poliomyelitis AFP should be at least 1 per 100,000 ('surveillance quality marker')
- ✓ If criteria are met and no cases of poliomyelitis are identified for 3 years consecutively, the country is declared free of poliovirus



**Photo 6:** AFP cases are reported to NPSP every week

## **2.4 Current situation**

After the experience of the outbreak in 2002, there were more enforcement of polio immunization in Uttar Pradesh by the government and the international organizations with more NIDs and 'mop-up' campaigns. Along with this, a new strategy of social mobilization was introduced.

### **2.4.1 Increased intensity in immunization**

Starting from 2005, monovalent oral polio vaccine type 1 (mOPV1) was integrated into the strategy replacing trivalent oral polio vaccine (tOPV) for SIAs to specifically target the spreading WPV1. In response to another outbreak in the country in 2006 with 676 new cases of which 648 cases were WPV1, use of mOPV1 was more intensified (CDC, 2007). This strategy is currently supported by one retrospective case-control study done by Grassly (2007) where mOPV proved to be three times more effective than tOPV in the context of Uttar Pradesh. In the study, the protective efficacy of mOPV was measured to be 30% [95% CI: 19-39,  $p < 0.001$ ] with per dose whereas it was 11% for tOPV [95% CI: 7-14,  $p$  value not given]. One striking result of this study was even with mOPV, which the result said to be more effective, it was only effective by 30%. Yet, it is difficult to draw a conclusion from this study because it was performed retrospectively where many assumptions were made during its analysis. Further, real efficacy of a vaccine could only be measured by seroconversion in administered individuals (Vancelik, 2007).

Nevertheless, after this introduction of mOPV1, the WPV1 cases are on the decline in Uttar Pradesh, with only 21 cases in 2007 compared to 520 cases in the previous year (CDC, 2007). However, as a side-effect of giving only mOPV1 during SIAs, the situation has been reversed and there is now a rise to WPV3. When there were only 28 cases of WPV3 in 2006, the cases increased to 316 in 2007 (Gol-WHO, 2008). As of July 5, 2008, a total of 79 cases of WPV3 were reported for the year 2008 while there was only one case of WPV1 (Gol-WHO, 2008).

Currently, SIAs are done using mOPV1 and mOPV3 alternatively. There were 2 NIDs and 8 SNIDs conducted in 2007 (e.g., almost every month).

## 2.4.2 Social Mobilization

Social mobilization was introduced into the Pulse Polio Programme because one of the reasons behind for ongoing cases of polio was believed to be children who were not reached by OPV. Some families were resistant to OPV for numerous reasons including rumours, fatigue from the repeated rounds, and apathy (Dasgupta, 2007; Kishore, 2003). Core elements of social mobilization involve interpersonal communication between families and

polio communication workers/influencers including religious leaders and community leaders (called Pradhans<sup>ξ</sup> in India), strengthening of state's infrastructure, and an engagement of mass media (UNICEF, 2007). House-to-house rounds done during SIAs are a part of social mobilization. Much work in this area is taken up by UNICEF and its subordinate organization, CORE.



Photo 7: '27 April Pulse Polio Day': yellow banners are everywhere a week before SIAs

## 2.5 Current concerns

As already mentioned in the Introduction Chapter, there have been several concerns raised for the Pulse Polio Programme recently.

### 2.5.1 Influence on the routine immunization

Increased workload from the Pulse Polio Programme is regarded to be taking part in the recent decline in routine immunization coverage. Some qualitative researches performed previously in Uttar Pradesh suggested health workers were overloaded with work from the programme, and this is affecting their other work including routine immunization (Dasgupta, 2007; Kishore, 2003).

Low coverage of routine immunization is an area of concern not just for prevention of other diseases but also for polio (Arita, 2006; IAP-PEC, 2008). It is known from past experiences that many developing countries which have eliminated polio had good coverage of OPV through routine immunization along with SIAs, including Bangladesh and Sri Lanka, the neighbouring countries known to be poorer than India (IAP-PEC, 2008). Thus, OPV given through routine immunization is regarded as a necessity for elimination of polio. Today, importance of routine immunization is advocated even more because tOPV which targets all three strains of poliovirus is administered in routine immunization, whereas SIAs only gives mOPV which is just for one strain (Puliyel, 2008). To establish comprehensive immunity against polio, a child has

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<sup>ξ</sup> Pradhans = Head of the Panchayati Raj Institutions (PRIs); traditional self-governing village bodies which leaders are elected by the community. Although the system was in India from the old days, their power diminished during the British rule. Enforcement for the system was made under the 72rd Amendement of the Constitution in 1992, again allowing them speak for their people.

to be immunized through routine immunization, and this is why many are concerned of deteriorating routine immunization coverage.

## 2.5.2 Rise of AFP cases

Number of AFP cases has been rising significantly especially from 2004 while only little change is seen in the number of WPV cases (Table 3). This is explained by surveillance achieving high levels of sensitivity, detecting every child who is suspicious of AFP (CDC, 2006). However, causes of non-polio AFP cases are not well documented, and some are raising concerns for possibly increased cases of VAPP and WPV cases misclassified as non-polio AFP adding to the figure (Mittal, 2007; Sathyamala, 2005).

Number of VAPP cases is unclear nowadays in India. Possibility for VAPP increases when vaccine virus is found from children's stools. However, this detection itself will not lead to diagnosis of VAPP because there are so many polio rounds almost every month with OPV recently that it is no surprise to find vaccine virus in children's stools. However, among the children who are identified with AFP and vaccine viruses are detected, there is a possibility that these children could have been affected by the vaccine virus. Numbers of vaccine virus cases are shown in Table 3 for the past several years, and some could have been VAPP. Also, however high the quality of stool exams is, there are still cases in which WPV could not be found from the stools leading to misdiagnosis. Children might not have been excreting poliovirus at the time of stool collection, or stool samples might have been in poor quality<sup>ξ</sup> (PAHO, 2006) Thus, these cases constitute some of non-polio AFP cases, which some researchers are considering the possibility of them to be taking part in the increased number of AFP (Mittal, 2007; Sathyamala, 2005).

**Table 3: AFP/confirmed polio/vaccine virus case count in India** (Source: WHO, 2008a)

Year	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007
AFP cases reported	1005	3047	9465	9587	8103	7470	9705	8508	13274	27049	32194	41529
Confirmed polio cases	1005	2275	4322	2817	265	268	1600	225	134	66	676	873
Vaccine virus cases	-	-	-	-	-	-	500	474	894	1644	1581	1747

\* In 1998, the number of AFP increased due to launching of AFP Surveillance.

\*\* Case definition of polio changed after 1997 from clinical basis (e.g., asymmetrical paralysis, residual paralysis) to cases with positive laboratory results for wild polio virus in stools. That is why confirmed polio cases reported in 1996 are documented to be equal to AFP cases.

## 2.5.3 Polio cases with immunization history

Polio cases are still found where there are poverty, high population density, poor sanitation, a large birth cohort, and high population mobility (CDC, 2007; Roberts, 2004a; Grassly, 2006). It is now clear that in

<sup>ξ</sup> Stool samples have to be maintained in a cool temperature in order for poliovirus to be kept alive and be detected from laboratories. If this process was inadequate, poliovirus may not be found.

these places, routine doses of polio vaccines are not enough to combat the disease. It is estimated around 85% of children who are affected have received more than three doses of polio vaccines earlier, and among these children, one-third had received ten doses or more (Arora, 2007). Roberts raised this issue in *Science*, 'In some of the toughest areas, transmission persisted even when the country managed to immunize 85% or 90% of the children, whereas in some parts of Africa it stopped with just 70% to 80% coverage' (2004; pp. 1963). Efficacy of the vaccine itself is questioned by some, but reasons for this phenomenon are still poorly understood (Roberts, 2006; Grassly, 2006; Pallansch, 2006).

## **2.6 Previous researches**

Despite rigorous search, there was no literature exploring what were the experiences of children after they were diagnosed with polio or AFP, and what were the perceptions of their families. One research by Kishore (2003) interviewed 10 families of children with polio in Uttar Pradesh, but the study's focus was on determining the reasons for occurrence of the disease. Yet, the study has found that none of the parents were aware of the importance of physiotherapy and feeling burdened by the expenses of their treatment. All cases belonged to the poor socioeconomic group with only one case with literate parents.

Some researches were found exploring perceptions of older patients with childhood-onset polio in industrialized countries, and they all described how quality of life decreased for these patients (Harrison, 2008; On, 2006).

## **2.7 Rationale for the study**

The Pulse Polio Programme is currently the biggest public health programme in India; the Government allocated Rs. 10.4 billion into this programme alone for the year 2008-09, and only 4.6 billion for all other five vaccines (GoI-MoF, 2008). Despite this much effort, the country has not yet succeeded in eliminating polio.

What is more, many AFP cases are being identified, in 2007 there were 41,529 cases nationwide and still increasing year by year, and not much is known about what is happening to these children and what care they are getting. It is clearly stated in literature from industrialized countries that their quality of life reduces after affected by polio, which will be no less for them, or even more having the same symptoms in poorer environment (Harrison, 2008; On, 2006). In addition, many of these children are whom they were promised they would not get the disease by having their 'polio drops'. Thus, it is important at this point of time to investigate on this issue.

## Chapter 3: Study Methods

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### Introduction

This chapter first describes the aim and objectives of the study, and then explains the choice of study design and the methods used. It further provides details on the process of analysis, quality assurance, ethical considerations, and challenges and constraints of the study.

### 3.1 Aim and objectives

#### **Aim:**

To describe the characteristics of children vulnerable to polio infection in Uttar Pradesh, India; and to explore what happens to children with acute flaccid paralysis (AFP) after identification under the surveillance system of the Pulse Polio Programme

#### **Objectives:**

1. To describe the characteristics of children identified with AFP and poliomyelitis
2. To explore experiences and perceptions of families whose children were identified as AFP with respect to the disease and the healthcare services they received after identification
3. To explore experiences and perceptions of healthcare providers and key informants from the community on the Pulse Polio Programme and children identified with AFP under the programme
4. To understand the health and social needs of children with AFP, especially those suffering from polio
5. To describe the healthcare services available for children with AFP and to explore barriers to their access
6. To present options to improve healthcare for children with AFP and to improve their quality of life

### 3.2 Study design

A number of different qualitative research methods and descriptive quantitative analysis were used to achieve the objectives of this study. The main focus was on qualitative research methods for its advantages in exploring and understanding diversity of views, attitudes, and opinions of people. Analysis and explanation building of qualitative research have a flexible nature which enables understanding of the context and the complexity of phenomena by putting pieces of realities together, giving holistic picture of the social world (Ritchie, 2003; Mason, 2002). The Pulse Polio Programme is a robust programme which involves people from diversity of backgrounds from top to bottom of the social class, which itself makes it very complex. Qualitative approach was appropriate in exploring such an arena of complexity.

Descriptive quantitative analysis was adopted for comprehensive understanding of the characteristics of children with AFP to complement findings from the qualitative methods.

### **3.3 Study location and timeframe**

Muzaffarnagar District was selected for this study for three main reasons. The district is classified as a high-risk area for polio by the NPSP, and they had the highest number of WPV3 cases in Uttar Pradesh in 2007 (Table 4) (Muzaffarnagar District Hospital, 2008). Despite this fact, there seems to be no research on this issue, focusing on Muzaffarnagar. In contrast, in several other high-risk areas such as Moradabad, Bareilly, and Jyotiba Phulenagar, there have already been several researches done using a similar study framework. Some studies have indicated that community members have developed a certain hardness and fatigue from the repeated rounds of immunization and frequent visits by investigators and researchers (Dasgupta, 2007). Muzaffarnagar was ideal to avoid these effects. Also, blocks in Muzaffarnagar were comprised of mixed population of Hindus and Muslims.

Data collection was conducted from 28<sup>th</sup> April to 18<sup>th</sup> May 2008 for total of three weeks. Another visit was made on 4<sup>th</sup> and 5<sup>th</sup> June for the aim to fill in the gap of information and to observe a Sub-national Immunization Day (SNID).

**Table 4: Confirmed polio cases in Muzaffarnagar from 2000-2007** (Source: Muzaffarnagar District Hospital, 2008)

YEAR	2000	2001	2002	2003	2004	2005	2006	2007
Muzaffarnagar	17	8	59	5	7	0	33	49
India	265	268	1600	225	134	66	676	866

### **3.4 Research team**

The research team was comprised of total of three people, the main researcher and two research assistants.

The main researcher gained knowledge and thorough training in qualitative research methods through the taught module for the Master of International Public Health course at the Liverpool School of Tropical Medicine. Medical background of the researcher also facilitated the research to a large extent.

Both research assistants were from the client's organization: male and female. The male research assistant was a Ph.D. student of International Relations at the Jawaharlal Nehru University and the female research assistant was a graduate of the Master of Arts in Sociology from the Jamia Millia Islamia

University in New Delhi. They were both fluent in Hindi, the local language, and also in English. Their abilities were competent to help conduct the research. In addition, due to the enormous amount of data, a professional translator with ten years of experience was hired to help the research team in transcripts and translations.

A training of research assistants was scheduled before the commencement of field work to make them familiar with the topic and with the research methods. The agenda covered by the training was as follows:

- ◆ Qualitative research methods: how to do interviews and FGDs
- ◆ Practical exercises using qualitative research methods
- ◆ Confidentiality and ethical considerations
- ◆ Framework of the research study
- ◆ Poliomyelitis
- ◆ Pulse Polio Programme

All the data collection was carried out in presence of the main researcher with both or either of the research assistants. The main researcher conducted the interviews with any participants who felt comfortable in speaking English. Otherwise, one of the research assistants conducted the interviews and also the FGDs, which were for most cases. The main researcher has taken field notes for all the interviews and FGDs.

### **3.5 Study population and recruitment**

Recruitment of all participants was done in collaboration with research assistants and with a local NGO based in the field introduced to the researcher by the client. The participants recruited for the study are shown in Table 5.

The main target group of the study were families of a child who was diagnosed with AFP in the past three years, irrespective of their final diagnosis (i.e., final diagnosis might or might not have been poliomyelitis). This group was identified by obtaining lists of patients from doctors at the primary health centres (PHCs) with consent from the District Magistrate and Chief Medical Officer. Total of six PHCs were visited, each from different blocks classified as high-risk areas. The study was able to recruit most families who met the above criteria. Consent from families were first obtained by the fieldworker of the local NGO and then by the research team.

Otherwise, the selection of study participants was performed purposively. Various healthcare providers

**Table 5: Participants of semi-structured interviews**

Target Group	Numbers
<b>Community</b>	
Family of a child who was diagnosed with polio in the past 3 years	17
Family of a child who was diagnosed with AFP but was given negative results for the stool test in the past 3 years	9
Family of a child under 15 years-old who has residual paralysis	18
<b>Healthcare providers</b>	
District Magistrate	1
District Immunization Officer (Deputy Chief Medical Officer)	1
International organization members	4
Primary Health Center (PHC) doctors	8
Private practice doctors*	4
Traditional healers	2
ANMs, ASHAs, Anganwadis	12
Block supervisors	2
Local NGOs	2
<b>Key Informants from the community</b>	
Religious leaders	3
Community leaders (Pradhans)	4
Journalists	2
Academics and researchers	6
Total	95

*\*Two interviews were conducted with two PHC doctors \*\*One block supervisor and journalist had a background as teachers.*

and key informants from the community were invited to participate, so the data would enable a detailed exploration and understanding around the topic.

Families with a child with residual paralysis were included in this study because they have more experience and understanding about the children's needs with paralysis, for it takes some years for children affected with polio to develop their symptoms and reach the stage of severe paralysis. Age was limited to under-15 which is one of the criteria for the AFP Surveillance, so it would correspond to those who are newly identified under the system. These families were identified by the local NGO and the same consent process was pursued as above.

In addition, focus group discussions (FGDs) were performed with mothers of children under 5 years old

from the community to understand the context of the study area. FGDs were organized by the local NGO.

## **3.6 Data collection methods and procedure**

### **3.6.1 Preparation**

The main researcher developed topic guides for every interview and FGD in English then modified through discussions with the research assistants. Topic guides were kept flexible throughout the research process, and if necessary, were revised and refined reflecting on the previous findings and performance to meet the research objectives. Adjustments were made according to the participant's background. Prior to every interview and FGD, topic guide was discussed again with the research assistants for any last changes.

Informed consent sheet was translated from English to Hindi before going to the field.

### **3.6.2 Data collection methods**

As mentioned earlier, data collection for this study was performed through semi-structured interviews, FGDs, direct observations, and secondary data collection and review. Following section describes more about these selected methods. A summary of this section is given at the end in Table 7.

#### **3.5.2.1 Semi-structured interviews**

Semi-structured interviews with family members of children with AFP (both polio and non-polio) and residual paralysis were conducted to retrieve in-depth and contextual information about the respondents' experiences, knowledge, and perceptions around their children's situation and other relevant issues. Also, various health providers and key informants from community were interviewed to gain in-depth information around the healthcare provided for children with AFP and other related issues including the Pulse Polio Programme and overall situation of healthcare in the area.

In total, 17 families of children with polio, 9 families of children with non-polio AFP, and 18 families of children with residual paralysis were interviewed. Each interview lasted between 15 and 20 minutes and took place usually in their homes or otherwise in a quiet place in neighbourhood of the families (e.g., yard, barn). As for the latter target group, a total of 51 interviews, 36 for the healthcare providers and 15 for the key informants from community, were conducted. Duration of interviews varied from 20 minutes to some with over one hour according to their knowledge and interest. The interviews with these participants took place in a quiet room in their hospital or office.

All the interviews were performed using topic guides (APPENDIX 4-5), and the interviewer prompted and

probed where necessary as the interview went along to get full understanding around the topic. Total of 74 interviews were conducted in Hindi, and the remaining 21 were in English. One respondent from the families of children with polio and three respondents from the healthcare providers did not agree to recording, but otherwise all the respondents gave consent on voice-recording their interviews. All the recorded interviews were transcribed and translated by the research team, and later with help from the professional translator. Field notes were made for the four interviews that were not recorded. Clarification and confirmation of the transcripts, translations, and field notes were made among the research members and the translator.

### **3.5.2.2 Focus group discussions (FGDs)**

Focus group discussion (FGD) was selected as a tool for generating information from mothers of children under 5 years old because it is a strong tool whereby provides group norms and social context around the topic by creating group dynamics (Ritchie, 2003). In this study, general health seeking behaviour and experiences/perceptions about healthcare provision in the locality were explored through FGDs.

Total of seven FGDs were organized according to their religious background and their living area with range of 6-9 participants in each group (Table 6). The groups were made to be homogenous because more group interactions and dynamics are created when individuals have things in common (Kitzinger, 1995). Each session lasted for 30 to 60 minutes and carried out either in a house or outside. Effort was made every time to find a quiet place which would ensure privacy, but sometimes there were interruptions by other community members who were curious about what was going on. Also, because many of the mothers brought their children, there were interruptions by children crying.

All FGDs were performed in Hindi and were facilitated by the research assistant. Topic guides (APPENDIX

**Table 6: Composition of FGDs**

FGD No.	Religion	Setting	Location	No. of mothers
1	Hindu	Urban	Purkazi	9
2		Rural	Jalbarpur	9
3		Rural	Kalyanpur	9
4	Muslim	Urban	Purkazi	8
5		Sub-urban	Karahbar	6
6		Rural	Harinagar	8
7		Rural	Godhana	7
Total				56

6) were used and another research assistant translated to the main researcher while sessions progressed to ensure all the key issues were covered. All FGDs were recorded with consent from the participants, and later transcribed and translated into English.

### **3.5.2.3 Direct observation**

Direct observation was carried out during the SNID on 4 June, 2008, and the research team accompanied one polio team<sup>ξ</sup> going house-to-house giving 'polio drops' to children. Observing real-life settings and interactions between community members and frontline healthcare providers enabled the researcher to generate a better understanding and also helped fill in the gap between the knowledge and the reality.

### **3.5.2.4 Secondary data collection and review**

Documents describing any kind of healthcare services that are available for or were given to children with AFP were searched and reviewed. Also, government documents on national policy for the disabled were reviewed.

### **3.5.2.5 Field diary**

The researcher kept a field diary with everyday events and informal observations. In addition, observations and impressions of living conditions and any other characteristics that would reflect on the socioeconomic status of participants were recorded for every interview and FGD.

### **3.5.2.6 Descriptive quantitative analysis**

AFP case investigation forms were obtained from the PHCs. They included immunization history and background information of children with AFP and were used to describe the characteristics of these children. (APPENDIX 7)

**Table 7: Methods used to achieve different objectives**

Objective	Methods used
1. To describe the characteristics of children identified with acute flaccid paralysis and poliomyelitis	Semi-structured interviews Field diary AFP case investigation forms
2. To explore experiences and perceptions of families whose children were identified as AFP around the disease and the healthcare services they received after the identification	Semi-structured interviews FGDs Direct observation Field diary

<sup>ξ</sup> Polio team usually consists of three people: ANM, ASHA, and Anganwadi. Sometimes another lady worker from the locality is chosen to participate in house-to-house rounds for giving 'polio drops'.

3. To explore perceptions of healthcare providers and key informants from the community on AFP and polio cases	Semi-structured interviews FGDs Direct observation Field diary
4. To understand the needs of children with AFP, especially those with polio	Semi-structured interviews Field diary AFP case investigation forms
5. To explore the healthcare services available for children with AFP and to explore barriers to their access	Semi-structured interviews Secondary data collection & review

### **3.7 Data analysis**

Data analysis proceeded along with the data collection. As Pope described, ‘continuous analysis is almost inevitable in qualitative research: because the researcher is “in the field” collecting data, it is impossible not to start thinking about what is being heard and seen’ (2000; pp. 115). This inductive approach enabled reflection of new findings on subsequent data collection procedures for further depth in the study.

After leaving the field, thematic approach was used to analyse the data in a systematic way. There were five stages to this analytic approach (Pope, 2000):

1. *Familiarisation*: Through the process of transcribing, reading and rereading of transcripts, and also from daily discussions with the research assistants, the researcher got familiar with the raw data and emerging key ideas and recurrent themes.
2. *Identifying a thematic framework*: Emerging key ideas, concepts, and themes were identified and made into a list. An index was produced from this list and was organised into a framework with the research assistants. (APPENDIX 8-10)
3. *Indexing*: Raw data was coded into appropriate index using the MAXqda software package.
4. *Charting*: A paper chart was used to rearrange data into three categories: (1) Characteristics of children with AFP and why they were affected, (2) Healthcare for children with AFP, and (3) Background information of the area including healthcare.
5. *Mapping and interpretation*: The chart above was used to define themes and concepts to create typologies, and then typologies were mapped out to see linkages between each. The researcher tried to interpret and explain certain phenomena through this process.

### **3.8 Quality assurance**

Principles of quality assurance and trustworthiness were imbued throughout the research process. Measures taken to ensure these are described respectively.

#### **◆ *Training and meetings among team members***

Training was provided for the research assistants before the commencement of fieldwork for them to have adequate skills in interviewing and facilitating FGDs to increase credibility and dependability in the retrieved data. Special attention was put on questioning process and technique. Meetings were organized to peer-check on the skills and to review gathered information from interviews and FGDs.

#### **◆ *Recording and field notes/diary***

Except for four interviews, all the interviews and FGDs were recorded. This enhanced the validity of data by avoiding data loss and misremembering of data. Field notes and diary also helped the researcher to remember informal information, impressions, and reasons for methodological decisions.

#### **◆ *Descriptions, clarifications, and double- translations***

Translation-related problems diminish validity of data (Birbili, 2000; Temple, 2002). Such problems included: lack of equivalent vocabularies or expressions from Hindi to English and influence of the interpreter's views on translations. To minimize such effects, detailed descriptions on Hindi-specific words and clarifications on any incomprehensible section in the translations were made with the person who was responsible for the work. Furthermore, translations were produced by two people for important sections.

#### **◆ *Triangulation of mixed methods***

Different qualitative methods (e.g., interviews, FGDs, observations) and also descriptive quantitative analysis were used for a means to cross-check information to reduce uncertainty and to ensure a reflective analysis (Pope, 2000).

#### **◆ *Reaching saturation point***

The study was able to reach a point where no more new information were coming out, and was successful in capturing range of experiences and perceptions from the participants.

#### **◆ *Transparent presentation of data collection and analysis***

Methods of data collection and analysis were openly and clearly presented for the readers to follow the logic and judge the quality of the study.

### **3.9 Ethical considerations**

The study was conducted with respect for every participant. Steps taken to assure this principle are discussed below.

#### **◆ *Ethical approval***

Ethical approval for this study was granted by the Ethics Committee of Liverpool School of Tropical Medicine before commencement of the field work.

#### **◆ *Informed consent***

All interviews were conducted following consent from the participants. The research team provided participants with information on the research, the research team members, and their expected role in the study. Any question asked was answered, and the research team tried to make participants fully comfortable in participation. Written consent was obtained, but verbal consent was used alternatively when participants were illiterate. (APPENDIX 11-12)

People's stance and views were respected in every way, and for those who did not wish to participate were not included in the study. Also, field notes were taken as an alternative for those who did not agree on recording.

#### **◆ *Confidentiality***

All materials concerning participants in the study were kept confidential to protect them from any social risks. To fulfil this responsibility, following steps were taken:

- ✓ All data were kept in a secure place under the responsibility of the researcher to avoid any disclosure. Electronic data were password-protected.
- ✓ Only the research team had access to these data.
- ✓ Anonymity was maintained throughout the whole process (at field, analysis, and reporting) by using unidentifiable codes rather than names when referring to participants. Quotes presented in the Results Chapter use names for a broader category in identifying owner of the quotes rather than referring directly to their professional backgrounds.
- ✓ Data will only be used for the research and will be destroyed after the study in an equally secure manner within 5-years time.

#### **◆ *Causing no harm***

The research team had to take care not to cause emotional distress in interviewing parents, for they are many times very anxious about their children (Long, 2007). All possible considerations were taken such as

avoiding any distressful questions and having at least one member from the local NGO accompanying the research team so at time of such happenings, she would be present to comfort the participant and provide appropriate follow-up if necessary.

### **3.9 Challenges and constraints**

Below are the two main and the biggest challenges and constraints the researcher faced during the study.

#### **◆ *Sensitivity of the issue***

The researcher was unable to interview a particular group of healthcare providers such as the Surveillance Medical Officers of NPSP, who were initially included in the study design, because the study did not have approval by the Government of India.

#### **◆ *Language***

Language was an apparent constraint to the study even before going to the field, but it turned out to be much more than the researcher had anticipated. Most of the interviews were done in Hindi, and it was difficult for her to have control over the kind of information being generated. Also, much informal information was missed out from talk before and after the interviews. Furthermore, some essence of the interviews was lost because many Hindi words did not have corresponding words in English; but also the dialect of Hindi spoken in the study area was very local and even the co-researchers had difficulties in understanding from time to time. This, and also illiteracy of families which made many interviews very difficult to understand with little information, created the necessity in conducting many interviews to fit in all the puzzles together into one piece (e.g., sometimes it needed 6-8 interviews to understand one piece of information).

## Chapter 4: Results

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### Introduction

This chapter presents findings in line with the objectives outlined in the preceding chapter. It is divided into six sections. The first section describes characteristics of children with acute flaccid paralysis (AFP) whose families were interviewed in this study. There are a number of issues surrounding healthcare services of the study area which should be understood before exploring healthcare services for AFP in particular, and these are reviewed in the second section. The following three chapters present the findings that this study was able to generate around healthcare provision for children with AFP from families' point of view and from providers' point of view with some others. Finally, the last section discusses the needs and suggestions for the children with AFP.

### 4.1 Characteristics of children with acute flaccid paralysis

The characteristics of children with AFP whose families were interviewed are shown in Table 8. Majority of children were under 5 years old, and children with polio were younger compared to non-polio: mostly under 3. Among the 17 cases of polio, 6 cases were type P1 and 11 cases were type P3. Irrespective of polio or non-polio AFP, most children were living in a rural setting, from a Muslim family many times from a very marginalized caste (e.g., Ansari<sup>ξ</sup>, Qureshi<sup>Ⓜ</sup>), and their parents were poorly educated. All of them received polio drops through supplementary immunization activities (SIAs), mostly more than 10 times, before onset of paralysis. Some believed they were also having protection against other diseases from 'polio drops', and some did not perceive other vaccines as important as 'polio drops'. Consequently, very few were going through routine immunization and were not having oral polio vaccines (OPV) from routine immunization. Families mentioned diarrhoea as the most prevalent illnesses among their children.

Common characteristics of children with polio described by healthcare providers and key informants were: poor, unhygienic and congested living conditions, illiterate parents, and poor nutrition. Many also mentioned they were mostly from Muslim families, but excused religious background from being one of the contributing factors. There was a time few years back when children from Muslim families were not taking OPV due to rumours (e.g., 'polio drops causes infertility'); but currently the situation had improved and almost all were accepting OPV.

From observation from visits to their houses, their living conditions were poor; most of the time, the families were living with the livestock, and there were myriad of flies. Their source of water was from hand

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<sup>ξ</sup> Ansari: considered a low caste among the Muslims, traditionally weavers and handcrafters

<sup>Ⓜ</sup> Qureshi: another low caste among the Muslims, butcher community

**Table 8: Characteristics of children with AFP**

Case No.	Age Notified	Sex	Stool Test Result	No.OPV (SIAs)*1	No.OPV (RI)*2	Living Setting	Religion	Education*3 (Father/Mother)	Occupation	No. of Children
<b>Polio</b>										
1	2 yr. 0m.	M	P3 Wild	12	1	Rural	Muslim	Illiterate / Illiterate	Juice vendor	7
2	11 m.	F	P3 Wild	6	1	Rural	Muslim	8th / 3rd	Farmer	8
3	1 yr. 0m.	M	P3 Wild	6	0	Rural	Muslim	12th / 10th	Labourer	5
4	2 yr. 6m.	F	P3 Wild	14	1	Rural	Muslim	9th / Illiterate	Farmer	4
5	1 yr. 6m.	M	P3 Wild	13	0	Rural	Muslim	8th / Illiterate	Labourer	5
6	2 yr. 6m.	F	P3 Wild	14	0	Rural	Muslim	Illiterate / Illiterate	Labourer	3
7	1 yr. 4m.	M	P1 Wild	8-10	0	Rural	Muslim	Illiterate / Illiterate	-	-
8	1 yr. 6m.	M	P1 Wild	8-10	0	Rural	Muslim	5th / Illiterate	Labourer	3
9	10 m.	M	P3 Wild	6	0	Rural	Muslim	Illiterate / Illiterate	-	2
10	1 yr. 6m.	M	P1 Wild	6-8	0	Rural	Muslim	Hindi / Illiterate	Labourer	9
11	6 m.	M	P1 Wild	16+	4	Rural	Hindu	9th / 5-6th	Farmer	3
12	1yr.10m.	M	P1 Wild	9	0	Rural	Muslim	8th / Illiterate	Shop owner	5
13	1 yr. 8m.	M	P3 Wild	14	0	Rural	Muslim	Illiterate / Illiterate	Labourer	5
14	1yr.	F	P3 Wild	6	2	Rural	Muslim	Illiterate / Illiterate	Labourer	7
15	2 yr. 0m.	F	P1 Wild	14	0	Rural	Muslim	Urdu / Illiterate	Pantry work	2
16	8 yr.	M	P3 Wild	15	0	Rural	Muslim	Illiterate / Illiterate	Rickshawpuller	3
17	6 yr. 0m.	F	P3 Wild	60+	0	Rural	Muslim	Illiterate / Illiterate	Mill work	-
<b>Non-polio</b>										
1	6 yr. 0m.	M	Negative	20-25	0	Rural	Muslim	Illiterate / Illiterate	-	3
2	1yr. 6m.	F	Negative	10	2	Rural	Muslim	Illiterate / Illiterate	Furniture shop	4
3	1yr.11m.	M	NPEV*4	12	3	Rural	Muslim	Illiterate / Illiterate	Tailor	4
4	3 yr. 6m.	M	Negative	20	1	Rural	Muslim	-	-	3
5	4yr. 0m.	F	Negative	20	0	Rural	Muslim	8th / Illiterate	Farmer	4
6	2 yr. 0m.	M	P3Vaccine	12	3	Rural	Hindu	BSc / BA*5	Engineer	3
7	4 yr. 3m.	M	Negative	24	1	Rural	Hindu	12th / 8th	Farmer	6
8	3 yr. 1m.	M	Negative	20	0	Rural	Hindu	-	Labourer	-
9	2 yr. 0m.	M	Negative	12	1	Rural	Muslim	Illiterate / Illiterate	Labourer	2

\*1 Number of OPV received through SIAs    \*2 Number of OPV received through RI

\*3 Education system in India: Primary – 1<sup>st</sup> Standard to 5<sup>th</sup> Standard (Age 6-11); Secondary – 6<sup>th</sup> Standard to 10<sup>th</sup> Standard (Age 11-15); Higher Secondary – 11<sup>th</sup> Standard to 12<sup>th</sup> Standard (Age 16-17)

\*4 NPEV=non-polio enteroviruses

\*5 BSc = Bachelor of Science, BA=Bachelor of Arts; both are graduate degrees

-pumps, sometimes situated very close to the livestock, and dwellings did not have any sewerage system. Their houses were many times made of mud or bricks without any electricity system, and were sometimes surrounded by piles of garbage or a dirty pond. The houses were alongside each other, and neighbourhoods were highly populated. More than five children were commonly seen just in one family, and most were living with their relatives. Many were having only big 'rotis' (one of the most common Indian bread) or plate of rice as their everyday meal. (Photos 8-12)

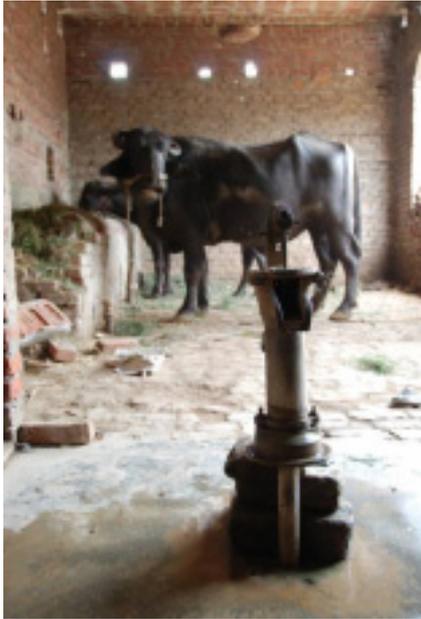


Photo 9 : No sewerage system

Photo 8: Hand-pump and the livestock



10



11



12

Photo 10: Stream where many children were playing inside

Photo 11: Children and the calf

Photo 12: This is one family.

Several cases could not be included in the study. One family with polio case rejected the interview, and another family was not found at the given address. One family with non-polio AFP had moved out of the village. There was one record where the child died immediately after identification (wild poliovirus was found from his stool), and the research team avoided contacting this family so as not to cause any distress. Characteristics of these families are given in APPENDIX 2.

## 4.2 Healthcare service of the area

The situation of available healthcare services in the area was explored through FGDs with mothers of children under 5 years old and through interviews with healthcare providers. Several distinctive factors shaping people's behaviour and healthcare structure emerged from both sides, explaining the situation from two different angles. These are described in this section, along with illustrative quotes.

### 4.2.1 Perception of the community

Characteristics of the mothers participated are shown in Table 9. Many corresponded closely to the characteristics of families of children with AFP.

Table 9: Characteristics of mothers in FGDs

FGD No.	Religion	Setting	Average age (range)	No. of literate mothers	Average no. of children(range)	Work
1	Hindu	Urban	28.3 (23-35)	4	2.5 (1-5)	Various
2		Rural	29.4 (25-35)	0	3.3 (1-6)	Farmer
3		Rural	28.6 (23-38)	0	2.2 (1-4)	Labourer
4	Muslim	Urban	30.6 (23-32)	2	3.5 (1-6)	Labourer
5		Sub-urban	32.5 (30-42)	0	5.5 (4-7)	Labourer
6		Rural	27.0 (22-35)	0	3.8 (2-9)	Farmer
7		Rural	37.5 (24-45)	0	3.7 (1-6)	Farmer

Health seeking behaviour was almost uniform among the community members. For minor diseases, they chose nearby village doctors, and if they did not get relief or for more severe diseases, they travelled to hospitals in town or city. Their preference to private hospitals over government hospitals was consistent. Reasons for not wanting to use the government hospitals are discussed below.

#### ◆ *Lack of medicines: both in quantity and quality*

Medicines are supposed to be provided to people free-of-cost in government hospitals, but many people had experience of being given prescriptions to buy them from pharmacies outside due to shortages and

also due to the limited selection of medicines usually available. Even when medicines were given inside, there was lack of faith in quality of the medicine provided, and people felt that they were not effective and would not give relief. Some also mentioned getting the same medicine for all kinds of diseases.

*“What’s the point in taking [the children] to government hospital? They write prescription and say bring medicine from the store. So money has to be spent whether the person is poor or has no money, they just write prescription.” (Hindu-rural)*

*“We don’t go to government hospitals much because diseases don’t get cured and they don’t give good medicine. Many children died because of lack of medicine.” (Hindu-urban)*

◆ ***Long distance and long queue***

Long distance to government hospitals was another concern for people because that meant loss of time and additional cost of transportation. Also, they had grievances against the long waiting time after they reach hospitals. They had no time to waste because many were poor and missing even a day of work would create much burden to their household.

*“If we go there then we get medicine from there, but then we don’t get time.” (Muslim-rural)*

*“The hospital is far away from our village, it is in Purkazi (town). We have difficulty in public transport and we cannot go quickly.” (Hindu-rural)*

◆ ***Lack of concern***

Many mothers strongly felt that government doctors were not taking time to examine their children properly, and moreover lacking concerns for them and their children.

*“Whether one has fever or dysentery, or whatever the problem may be, they don’t check with stethoscope or anything, whether they have the machine (means) or not. They just come, give medicine, and whether the child has pain or problem or child’s mother is having any problem, they are not bothered. They just pick up the bottle and start drip.” (Hindu-rural)*

*“They don’t look at the person, how are they bothered about the disease. They’ll just give two tablets and say off you go. You have been given medicine, go now.” (Muslim-rural)*

◆ ***Doctors not present in hospital***

People indicated doctors were not present in the out-patient-clinic many of the times, and they had to wait for a long time to be seen. Sometimes they had to even go back home without being seen.

*"You have to run after them or keep on sitting (waiting) because they are having 'dais' meeting or some other meeting\*. They don't sit there. \*\*" (Hindu-urban)*

*\*Implying the meetings doctors are attending for the Pulse Polio Programme*

*\*\*Meaning they are not in hospital. This term was often used by the community members.*

*"Government doctors in government hospitals don't give medicine. We come back just as we go. They don't even sit properly." (Hindu-urban)*

#### ◆ *Referrals to other hospitals*

Some people gave getting referrals to other hospitals, including private hospitals and upper level government hospitals which are much far away, as one reason for avoiding using government hospitals.

*"In government, not so much money has to be spent, but they say 'we can't manage, take somewhere else.' If the child is serious, they don't admit and immediately refer to private...Poor people, where will we get such money." (Hindu-rural)*

#### ◆ *Private hospitals : good medicine and quick treatment*

Most people preferred going to private hospitals because there they got good medicine and quick treatment. Though they had to pay more compared to government hospitals, this was not much concern to them. They had to pay for medicines in the government hospitals anyhow, so they had this common feeling: why not go to the private in the first place. Their priority was to have their children's recovery as quickly as possible.

*"[Private doctors] take more money and give costly medicine so one gets relief. However poor people may manage, whether we take on interest, loan, or borrow or do whatever, we have to get our children treated." (Hindu-rural)*

#### ◆ *Acceptance of 'polio drops', less awareness for other vaccines*

All people participated in the FGDs were accepting the benefits of 'polio drops'. They were aware that it was given once a month, two drops each time, and that it was to prevent polio.

*"Polio (referring to 'polio drops') is a good medicine. There are so many children, but there has been no problem. Earlier there was problem with somebody's leg or hand or whatever; at least that is not happening now. By god's grace, children are now safe. Isn't that right? Otherwise earlier, things were not so good." (Hindu-rural)*

*"We are not forced to take 'polio drops'.\* They give for our benefit only, so that our child is successful in the future and his hands and legs remain healthy." (Muslim-urban)*

*\*This comment was made because earlier some force was used for giving 'polio drops' (e.g., by police).*

Most groups made a remark that there were some mothers in their locality, especially the Muslims, who were still hiding their children when polio teams were going house-to-house because the 'polio drops' would cause infertility in their children. They did not want name anybody because those mothers would come and 'fight' with them.

However, even amongst the mothers in the FGDs who were accepting, they were getting tired of the frequent rounds. Some ironic comments were made:

*"Only 'polio, polio'. They will come twice a month if that's their wish!" (Muslim-urban)*

*"They have no other work other than coming to house and catching children to give the polio drops. If this was in their hands, they will give the drops to the mothers also." (Muslim-urban)*

Awareness for other vaccines differed from group to group. Some groups had better awareness compared to others. Though they were not able to name what kind of vaccines there were, they were visiting either government or private hospitals to give 'injections' to children. They were made aware by the ANMs during house-to-house rounds and some named private and government hospital doctors as their source of information. In contrast, some groups were confused if they had given their children other vaccines, and some were mistaking 'polio drops' from routine immunization when answering to the question. Levels of education seemed to correspond to the levels of awareness for routine immunization.

*"ANM just tells us to 'vaccinate, vaccinate,' and nothing else. Even when we ask, they have no time to answer. They never explain us. We don't know what we are giving to our children. We are blind." (Muslim-suburban)*

#### **4.2.2 Perception of the healthcare providers and the key informants**

Interviewing PHC doctors and ANMs, the frontline healthcare providers under the government, revealed problems they had been facing while performing their work. These provided explanations to why some situation described above were faced by the community. Further, inputs from other healthcare providers and key informants helped create an overall picture to what kind of healthcare are provided for the people.

◆ *Lacking supply of medicine*

Through interviews, it became clear that there were shortages in medicines supplied by the government to hospitals, and many expressed the need for more supply to overcome this weakness. One important reason behind these shortages was high demand due to large population. Also, some mentioned difficulties in having only limited variations to what they could prescribe to their patients.

*"You see, people who go to government hospitals are mostly poor people and our supply is also not that good, and moreover we have limited stock. They demand for good medicine but what we have is the Government's supply only." (International Organization)*

*"For small children, syrup is necessary for them, but we have less supply of syrups. We have to then give tablets only, and we have to explain to them that they should crush/grind tablets and then give to children...And poor patients, who come here, mostly ask for syrups because children can have it easily." (PHC)*

◆ *Lack of manpower*

Lack of manpower in government hospitals was an issue brought up from every level of healthcare providers. The government had not been appointing health functionaries for many years, and many posts for doctors and ANMs were vacant though hospital buildings were there. As original staffs were retiring nowadays, more workload was imposed on the remaining workers.

*"The building in which we are sitting is meant for CHC (Community Health Centre which is higher level than PHC), though staff has not been deputed yet." (PHC)*

*"Our population here is more than 2.5 lakhs and we have total 24 ANMs or basic female health workers. So they have to cover about 10,000 population\* or more and they have other work as well." (PHC) \*There should be 1 ANM for every 5,000 population.*

◆ *Effects from the Pulse Polio Programme*

Workload

All PHC doctors commented that workload of the Pulse Polio Programme was affecting and hampering other daily works such as outpatient department (OPD) and routine immunization. The programme runs for one week almost every month, and for that, they had to attend various meetings and train vaccinators each time. They all had a very close estimate that around 15 days per month were consumed due to these activities. During this time, there were less people to carry out OPD and sometimes had to refer patients to other hospitals. The situation was similar for the ANMs.

*“Our other health services do get affected by this because we will involve all the doctors in polio. They will keep working from morning to evening. So then, we become dependent on pharmacist for our OPD.” (PHC)*

*“In 28 working days, 50% of our time is spent on this programme. During the Pulse Polio Programme, we are engaged from 8 o’clock in the morning to 6-7 o’clock in the evening. Due to this, our OPD work and various schedule hamper. There are lack doctors to carry out the OPD and other various functions in the PHC.” (PHC)*

*“Our daily routine work does get affected. All the doctors are out for polio duty; our mobility increases. So during that time, we sit less in OPD.” (PHC)*

#### Effects on the Routine Immunization

In addition, many healthcare providers and also key informants from different sectors of society held perceptions that the Pulse Polio Programme was having a considerable effect on the Routine Immunization Programme of the area. Of course one reason was the workload because only the same health workers were available to take care of both the programmes, but there were other critical reasons. The Routine Immunization Programmes were organized on every Wednesday and Saturday, but alternative arrangements had to be made for the week of the Pulse Polio Programme; moving these days to some other days of the following week. However, even these rearrangements were made to compensate the lost days, people would not show up because they were not aware. Also, those who showed up during the Pulse Polio Programme had to be sent back simply because there was no one to give injections to children.

*“So we try our best, we should not miss the Routine Immunization Days. But sooner or later, the staff is the same, ANM is same, people are same, then various types of programmes known in particular area ...either this or that programme has come to some ‘bare foot’ (functions are unprotected)...The Routine Immunization Programme is suffering.” (District level provider)*

*“Like Wednesday and Saturday are Routine Immunization Days, but if we have some other meetings (for Pulse Polio Programme), then we have to shift immunization days to Friday and Monday. So then people are not aware about it, since they know routine immunization is on Wednesday and Saturday. Sometime we have to change it suddenly because of meetings or trainings. So then programme gets affected.” (PHC)*

*"[The Pulse Polio Programme] does affect my work...Suppose child come for routine immunization at that time he has to go back, he will be immunized afterwards only." (ANM)*

Some other effects of the Pulse Polio Programme on routine immunization were recognized by some health workers that it developed a 'false impression' of vaccines and a 'certain mentality' among people. Their observation was that many illiterate mothers believed they had given all vaccination to their children because they had given them the polio drops; they had this misconception that polio drops were for every disease.

In addition, a large number of people have become used to the fact that health workers come to their doorsteps to give the polio drops; therefore do not feel the urge to go to the immunization 'booth' for polio drops and for other immunization.

*"When first vaccine is given at booth, due to less literacy of this place, few people turn up with children for taking vaccines. They think that these sisters (ANMs) will come to home to give drop to child so why go to booth and waste time, whereas we try to ensure that maximum child should take polio drop at booth only." (ANM)*

*"There is less awareness amongst the mothers. For example, if we tell them to bring their children to the Booth, they will not bother much and they will continue doing their own work. They don't realize the importance of it. If they don't go to the Booth they know tomorrow the team will come home to give the drops." (International Organization)*

Despite these difficulties, however, many of the health workers were confident that the routine immunizations were going well, side-by-side with the Pulse Polio Programme. On the other hand, key informants from community, especially the academics, expressed their anxieties for the deteriorating coverage of routine immunization.

◆ ***No specialist, less facilities in the lower level***

There were no specialists appointed at the PHC level or sometimes at the CHC level. Therefore, some doctors at these levels have acknowledged that they sometimes had difficulties in managing cases with their limited knowledge and technique. However, there were also situations where a doctor had the skills, but infrastructure of the hospital was inadequate to put these skills into practice. In such cases, they had no choice but to refer patients to other hospitals.

*"We try to do proper diagnosis with common perception basis regarding prevalent diseases, and we prescribe medicine with our assumption. If they respond to treatment, then it is all right. Otherwise, we send them to the District Hospital or to the nearest CHC. Due to this, patients have to travel long way. They don't have facilities for specialized treatment at the nearest PHC." (PHC)*

### **4.3 Experience and perceptions of the families of children with AFP**

This section uncovers experiences of families whose children suffered from AFP and kind of feelings that were associated with these experiences. It is presented in a chronological manner following their experiences step by step; from the first moment they detected paralysis in their children to when they got the final diagnosis.

#### **4.3.1 Early stages of paralysis**

The section below illustrates some experiences of families when they first realized that something was wrong with their children and their first access to health facilities seeking for treatment.

##### **◆ Onset of paralysis**

For most people in the local community, paralysis was equal to polio though there are various other diseases that cause paralysis; because prevalence of polio was very high in the area. Therefore, when families noticed that their children were 'falling down on the ground' or 'air was coming out of the legs', as they often described paralysis, the first thing they suspected was polio. One mother explained:

*"He got up in the morning and he turned on his stomach. He tried to move towards me, but he could not move. I was kneading flour, and I wondered as to what happened. He used to get up and walk, but why isn't he moving now. It suddenly struck me that he's got polio. I immediately took him down and left him with another boy of his age. I thought let me see if he plays. He used to run by holding on to the cot. But he could not move. I thought to myself that seems like his leg has got polio. I thought what has happened." (mother of 2 yr. old child with polio (P3), identified 10 m. before)*

People believed that once affected by polio, a child's whole life would be 'wasted'. From this fear, most of the families sought for an immediate care after seeing their child with the symptom. One grandmother recalled her memories:

*"In the evening, when I asked him to sit, he couldn't sit; he sat by taking support of wall. Then the next morning, I said that he is not able to sit without the support of wall, if he was to stand he fell down. Then I said to myself, 'I sense symptoms of polio.' Then I said I would take him to a doctor. Then father of the child said, 'Mother, let me consult the lady who gives polio drops.' Then Anganwadi worker said, 'I don't think that child will have polio especially when he is taking drop regularly. I am calling lady doctor (ANM), who is in the field.' Then that lady doctor (ANM) inquired 'Where is the child?'... She inquired if I had given medicine or injection. I said to her, I am ready to take." (grandmother of 3 yr. old child with non-polio AFP, identified 4 m. before)*

#### ◆ First access to health facilities

When asked about families' experiences around accessing hospitals at onset of their children's diseases, range of experiences were heard. Some families accessed government hospitals, but by and large, many families had approached private hospitals or their village doctors first rather than the government hospitals; the same health seeking behaviour that was seen among the general population.

However, under the system of AFP Surveillance, whoever was suspected of AFP had to be reported to the District Hospital, the top government hospital of the district, and stool test had to be performed for diagnosis. This rule was understood universally among practitioner in the area, which was also confirmed through interviews with them. Therefore, even the families made access to private practices in the beginning, with just a few exceptions with some village doctors, referrals or phone-calls were made to the government hospitals and the families were either made to go to the government hospitals or were visited at their homes by the government doctors.

*"Private doctor said that we would be fine so you take her to government hospital...He wrote prescription (a referral letter) and made us call [the District Hospital]. We told them he asked us to. Then the car came in the morning. Lady doctor (ANM) came and big big doctors came." (mother of 2 yr. old child with polio (P3), identified 11 m. before)*

Sometimes access to government hospitals was facilitated by ANMs and other field workers.

#### 4.3.2 'No peace of mind' at government hospitals

Given this system, all families had experiences around using government hospitals or seen by government doctors at their homes. The doctors examined children and stool samples were taken for all cases. However, most families did not continue their visits and went on with treatments from private doctors because there they did not get 'peace of mind' going to government hospitals. Many families were highly dissatisfied with the services and attitudes they experienced there. One of the main reasons behind this

was unavailability of medicines. Almost all families complained that they did not get any medicine from the hospital as this father expressed his anger:

*"The government doctors refused. They didn't give any medicine. They didn't give injection nor did they give any tonic for strength. They said that his prevention is the only cure for this. They just did stool checking...Hospital provided no help." (father of 3 yr. old child with polio (P3), identified 10 m. before)*

However, it became clear for some cases families were describing their situation as they were given 'no medicine' even though they were given prescription but had to buy the medicines outside. Prescription meant little to them, and moreover, they did not consider these medicines they had to buy out of their pockets as treatments they received from the government hospitals.

Also, many had a feeling that no attention was paid for their children. There was minimal interaction between the doctors and the families, and most families mentioned they were only told of their children's status, that their children had polio, otherwise not much more information. This family was getting medicines for their child from the government hospital for 5-7 months, which again they had to buy from outside many times, but the father showed more irritation to the behaviour of the workers at the hospital.

*"Let me tell you the real story. I must have taken her there at least 20 times. They don't even like to talk there. When I used to take her there, I used to take this paper (a referral note). They had kept those papers for three days; it was showing for three days. It's just people pushing around. Staff who're just like peons, they keep pushing people.\* [Then,] just take hand and give medicine. There is no interest. It's not okay, it's a polio patient so examine her carefully or give attention. That's not there." (father of 3 yr. old child with polio (P3), identified 10 m. before)*

*\* He means they had to wait for a long time among many others. From observation, the District Hospital was very crowded, and people were waiting outside the hospital sitting or standing waiving their referral letters or papers showing their turn.*

Furthermore, at PHC levels, families were told that their children cannot be treated there because it was not in their 'capacity'. This is revealed in one mother's response:

*"I saw her leg, it kind of limped to a side. Then I called her father and sent them to [government hospital]. She went there and doctors made her walk; she could walk slowly. They gave medicine [for one day] and she came back. We went again next day and then they refused. They said she could not be treated here. You may go and show her some place else." (mother of 3.5 yr. old child (P3), identified 10 m. before)*

On the contrary, stool samples were asked to be taken for this girl child, and a doctor from this PHC had visited her house to collect the samples. The mother further expressed her disappointment that:

*“...they only gave the box for storing sample.”*

However, for few cases among the families who received similar responses from the PHC doctors, it became apparent during course of the interviews that they were told to go to the District Hospital (e.g., it is PHC doctors’ duty to report cases of AFP to the District Hospital), which families had taken their words as they should go seek treatment somewhere else.



**Photo 13:** Box for stool testing; inside are four ice packs

### 4.3.3 Visits made by healthcare providers to their houses

#### ◆ Stool test and follow-up

Many visits were made by government healthcare providers to the children’s houses after they were identified with AFP. Families gave a list of people who visited them, and among those were doctors from the District Hospital, PHC doctors, and ANMs. There were also some occasions when they were visited by people from outside the district.

*“Doctors came from Muzaffarnagar (District Hospital) and other places as well. They used to come every 3<sup>rd</sup> or 4<sup>th</sup> day.” (mother of 2.5 yr. old child with polio (P3), identified 1 yr. 6 m. before)*

There were some variations to how often families were visited during the period while they were waiting for the stool test results to come. Some were getting many visits like the above, while some were getting only a few.

*“No, no doctor came.....No, one had come only once. After that, nobody came.” (mother of 3.5 yr. old child with polio (P1), identified 1 yr. 11m. before)*

Nonetheless, many families did not understand why they were visited because neither medicines, prescriptions, nor anything were provided for them. Excluding the first few visits which were for stool collection and which the purpose was also obvious for them, for other visits, families typically described these visits as ‘doctors come, just glance at the child, and go’.

*“One lady had come from the city, but we didn’t understand anything that day. They didn’t give any medicine nor did they..... We didn’t understand anything what they were saying.”  
(grandmother of 5 yr. old child with non-polio AFP, identified 6 m. before)*

*“Teams of doctors came many times in cars, sometimes four sometimes two, sometimes six for checking. They checked. They all came to see our child. But nothing at all was given. They would come and see, check his leg, take measurement and all and go back.” (father of 3 yr. old child with polio (P3), identified 10 m. before)*

There were just two cases where some kind of medicines was given to the children. One mother shared her experience:

*“Many big big doctors had come to see my child. One of the big doctors, I forgot his name, gave a bottle of medicine and my child got much relieved with that medicine.” (mother of 2.5 yr. old child with polio (P3), identified 7 m. before)*

◆ **After confirmation of diagnosis**

Two families said that they did not receive the report, but otherwise all families were visited at their homes with the stool test results on ‘paper’. Some remembered what they were told at that time and shared their experiences.

*“They said it’s your child and you can show him where ever you like. He doesn’t have dangerous polio\*. It’s still in limits and the child will be cured. He will be all right. After that they didn’t give any medicine to anything...They said you can show him where ever you like. And there is nothing specific. He may or may not be cured.” (mother of 2 yr. old child with polio (P3), identified 10 m. before)*

*\*Type P3 is considered to be less severe.*

*“They just said that this is not curable but you keep all these papers carefully. If the girl becomes disabled then she will get pension... Instead of giving her any treatment, they were thinking about her becoming disabled!” (grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)*

After this visit, the frequent visit by the doctors stopped for many families.

#### 4.3.4 Financial burden

Financial burden was a common theme emerged from every interview. This was a cost incurred on the families because they preferred going to private hospitals. Most of the families were poor with their income being usually around Rs.50 to 100 per day, while they were paying more than Rs.500 per visit for doctors. It is not difficult to imagine how much of burden the cost of treatment for children with AFP was to the families.

*“Lot of our money is going in for the child for doctors and medicine... We have spent so much money on this child. We don't have that much strength, we are poor people.” (father of 3 yr. old child with polio (P3), identified 10 m. before)*

Sometimes the families had to manage either by taking debt or stopping treatment for their children, or by selecting which treatment they would give to their children according to cost.

*“We stopped since we can't afford it anymore. Either we can eat or give her medicine. We have not been able to pay of money we had taken earlier for her treatment. Now you see what happens in 50 rupees earning.” (grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)*

Some families were using government hospitals, but nevertheless they often had to pay for medicines and for transportation, which still was a burden for such families. One father commented:

*“We haven't got any help from anybody. Whatever we are spending, we are spending it from our own pocket. Everybody wants to take money. Those who are sitting in government hospital they also gave 700 rupees medicine in a week.” (father of 6.5 yr. old child with polio (P3), identified 5m. before)*

As this father mentioned, there were no financial help provided for families with these children; at least among those who were interviewed in the study.

#### 4.3.5 Why did our children get affected?

One of the biggest concerns with the children who were affected by polio virus is the fact that they all had received over 10 to 20 doses of polio vaccines and still were affected. This of course was the big question in the families' mind which they wanted somebody to answer. Further, it was causing extreme anger among the families, having their promise broken that polio drops would save their children from getting paralyzed. One mother showed her anger:

*"I then asked [the doctor] when I have never stopped him from taking polio drops, then how come he got polio! We gave injection and medicine (polio drops), then tell me how he got polio. Now treat him, give him medication for his disease." (mother of 3 yr. old child with polio (P3), identified 10 m. before)*

She then recalled the response she got from the government doctor for this inquiry which increased her anger:

*"[The government doctor said] what you have to do with that. Now, what has happened has happened. You might be in contact with some polio people in your neighbourhood and your child might have got germ from there. Now tell me how you can stop children. Who gets what from whom, how would you know? Who can stop them? They are children, you see, and they go out of house, no matter how much you try to stop them."*

Likewise, this is another mother's experience:

*"I asked them how can she have polio? She has been having drops and she had vaccinations. Her name was written down when she was born. When she was born lady doctor (ANM) had come to house and gave her drops and also wrote her name. So I asked then how can she have polio, you tell me? If we are not giving drops and child gets affected we can't do anything. They said its 3 type. I don't know what that is. We are illiterate people. We don't know anything." (grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)*

In fact, many families were not able to obtain satisfactory answers. Sometimes no answer was given, and sometimes blame was put on them. These included possibility of mothers missing out polio drops, which they were sure they had not, and possibility of their children not having been swallowing polio drops properly. However, the most common answer was that it was in 'God's hands' or it was their 'destiny':

*"They said: 'what can we do?' The doctors here said its god's will what we can do. They said there will be no complaints from this side as all your children had taken medicine (polio drops)." (father of 2.5 yr. old child with polio (P3), identified 8 m. before)*

*"They just said it was his destiny. Now we can't do anything and you can't do anything. They would just say that and leave." (mother of 3.5 yr. old child with polio (P1), identified 1 yr. 11m. before)*

## 4.4 Perceptions of the healthcare providers and key informants on 'AFP cases'

In contrast to the previous section, perceptions of the healthcare providers, the providing side of the AFP Surveillance, are explored here. Also, information obtained from key informants is used to help complement the findings.

### 4.4.1 Importance of AFP Surveillance

All healthcare providers were aware of their role in the AFP Surveillance and how the system worked. They were generally feeling confident about the system. This was especially strong among doctors regardless of public or private or their position, and described the system as a 'well-established' and 'very much systematized' data collection system.

Every doctors interviewed at the periphery level believed it was their duty to be alert and not to miss any children with AFP. One doctor stated:

*"If there is any children even if, because it is also in the WHO guidelines, even if you are thinking it's not an AFP case, you have to send, to minimize the risk of the polio. Two stool samples, 24 hours apart, to the WHO laboratories, to confirm that if he or she is AFP or not." (PHC)*

Also, they indicated the importance of informing the District Hospital and the NPSP-WHO office in the district as described by this doctor:

*"Once it is clear that it is a fresh case of AFP, same day same time, we inform WHO and our district level, DIO (District Immunization Officer)." (PHC)*

Furthermore, all doctors and international organization members, those who were involved in the diagnostic process of AFP, stressed on the importance of stool samples, called them a 'must', and explained how they had to be done in a timely manner according to guidelines. This is well expressed in the comments given by doctors:

*"At the level of PHC or CHC, our medical officer is there, they attend the AFP case, and then they classify the case on the clinical ground whether the diagnosis is meeting and stool sample is done in 'each and every' case of AFP within 48 hours...We have to collect the stool as early as possible. Guideline says, we should collect the stool within 48 hours of the notification of the case." (District level provider)*

*“Unless until stool is not coming positive, nobody says he or she is polio or not. We see the children, we give some medicine, but when there is a disease, our first priority is to send his stool.” (PHC)*

On the other hand, when ANMs were asked about the AFP Surveillance, they explained that their role was to inform their nearby PHC ‘first and foremost’ if there was any case suspicious of AFP, which role they were fulfilling. However, besides this, the work was not in their level, and did not have much idea around diagnosis and treatment of children with AFP.

The work of the AFP Surveillance is completed in the 60-day follow-up visit to children’s houses as explained by this doctor:

*“Final follow-up is done, on 60<sup>th</sup> day of the all sort of AFP. All sort of symptom, rather. In last follow-up that is on 60<sup>th</sup> day, all the motor powers, sensory powers, or atrophy, either the circumference of the arms or circumference of the thighs, is done, so we have to see that patient has developed atrophy or not, or going to develop atrophy or not. So, last follow-up is done on the 60<sup>th</sup> day.” (District level provider)*

#### **4.4.2 Benefits of AFP Surveillance for children with AFP**

Many health providers perceived AFP Surveillance as beneficial to children who were identified the symptom under the system as one district level provider mentioned:

*“In both cases, whether it is polio or whether it is AFP, non-polio AFP, the benefit goes into the benefit of the programme as well as in favour of a child.” (District level provider)*

Common reason behind this perception was that the providers believed children identified were able to receive services which they could not have if they did not come under this system. These services included diagnosis being done free-of-cost, but also certain things such as attention of doctors.

*“And meanwhile, we are giving them some extra medicines and sympathies, and other all sorts of things to this family and that family, all things.” (PHC)*

*“As you know, AFP cases are very important for us. We are giving more and more and more attention to that child, so I think there is no lacking or there is no gap for the health point view of that child.” (PHC)*

#### 4.4.3 Who is providing treatment? And whose responsibility is it?

It is natural to have this question come up into one's mind when someone was diagnosed with a disease. When this issue was explored, though doctors at PHC were giving treatment also, it became apparent through interviews with private doctors and other key informants that more children with AFP were looked after at private hospitals. One private doctor revealed:

*"Government doctors diagnose and they send the children back home, that's all. In most of the patients, which we have been referring to hospitals, they will take samples of stools, they will diagnose whether it is a case of polio or not, and they ask them to go back to their doctor. Most of the time, they are not giving any treatment to that patient, or patient may not be following that may be the reason. But most of the time, I have seen that patients come back to us only without any treatment." (Private doctor)*

Hence, despite these children's diagnostic processes were taken under the AFP Surveillance, many children seemed to have not benefited from being identified as AFP in terms of treatment. This is because the AFP Surveillance is purely for identifying AFP cases to avoid spread of polio viruses. One academic described the AFP Surveillance as:

*"Their sole concern is this: whether they find the virus or not." (Academic)*

The role of the WHO, which is the main organization running AFP Surveillance, was clarified by one of its members:

*"The WHO has no supportive role in treatment or care. Families can seek for treatment in either private or public depending on what is available to them." (International organization)*

Collecting all the information together, it may be said in conclusion that there was no defined route, rule, or system through which children identified with AFP could seek necessary treatment following their diagnosis under the AFP Surveillance.

#### **4.5 Healthcare services currently available for children with AFP**

For this section, information was gathered together from all interviews and also from government documents and other literature to explore what kind of treatment, support, and care were currently available for children with AFP in India. Interviews with families with residual paralysis were especially helpful in developing this section (Characteristics of these families are given in APPENDIX 3). Findings

from this process are presented in the first two sections. Then in the final section, actual experiences of families with AFP around support and care are illustrated to examine the gap between the two.

#### **4.5.1 Treating children with AFP**

In addition to paralytic polio, there are mainly three other conditions that present with AFP, and these are Guillain-Barre syndrome, traumatic neuritis, and transverse myelitis as mentioned earlier. In addition, AFP sometimes manifest as side effects of drugs, and sometimes no definite diagnosis can be made. The research found that often AFP patients were treated according to symptoms they presented with.

As there is no specific 'anti-viral drug' to cure paralytic polio, a diagnosis that confirmed polio was a challenge shared by every doctor in treating each child and interacting with their families. Supportive and symptomatic treatments were given including antibiotics, analgesics, and nutritional supplement in form of calcium and additional protein. Adding to these were vitamin B1, B6, and B12 to support normal neuro-development and sometimes zinc to enhance auto-immunity, though these treatments are not well evidenced (Boines, 1953; Hansen, 1982). Only one traditional healer who was called the 'polio expert' by people mentioned about the importance of physiotherapy, which is one of the key treatments for polio. Few families mentioned about being told of doing exercises at their homes, but were not told how.

Among the 17 polio-affected children who were contacted in this study, 14 children showed symptoms of paralysis at the time of visit, and three children had almost complete recovery. All these three children were classified as suffering from type P1 wild virus: the type known to cause more severe paralysis than type P3. Through interviews, it became evident that these children had been provided thorough treatment by the doctors. On the other hand of the children who were diagnosed with P3 virus, four children out of 11 were receiving little treatment, and their parents claimed that the children's paralysis was gradually deteriorating. All children receiving some kind of treatment were showing improvement. Therefore, though the treatments were symptomatic and supportive, they seemed to be helping children in strengthening their immunity and power in the recovery.

Out of nine children who were diagnosed as non-polio AFP with their stool test negative for wild poliovirus, one female child presented residual paralysis at the time of visit by the researcher. It was four months after manifestation of AFP. She was not getting any treatment. Her mother did not take her to hospital despite her condition because she was told her child did not have polio by doctors when she received the result.

#### **4.5.2 Support and care available**

Through interviews with healthcare providers and key informants, government policy documents, and other related literature, several support and care available for polio-affected children were identified.

⌘ **Physical handicapped certificate under the Persons with Disabilities Act, 1995**

Under this Act, mobility aids including tricycles, wheelchairs, and crutches are provided by the government. Also, right to free education till age of 18 years is ensured. (Gol-MoSJ&E, 2008)

⌘ **'Health camps'<sup>ξ</sup> for mobility aids**

Distribution of mobility aids are done through 'health camps' by the government or by social organizations (e.g., Rotary Club, local NGOs, etc.), sometimes in collaboration between the two.

⌘ **Free corrective surgeries**

Several social organizations organize 'health camps' for corrective surgeries. Some doctors in the study area mentioned about a new scheme by the government for corrective surgeries for polio-disabled children, and they have sent a list of patients who would be eligible. From a government document that was accessible and from newspaper articles, there was a scheme introduced in 2006 whereby the government had allotted Rs.20 million for corrective surgeries for the polio-affected children in Delhi (i.e., city). (Gol, 2006; Roy, 2007; IANS, 2006)

However, many individuals including ANMs, Pradhans, international organization members, and journalists, were unaware of these services and were incapable of providing information.

*"The fact of matter is that, I don't have much idea about this subject. We are not provided information." (Worker for International Organization)*

### 4.5.3 Support and care experienced by families of children with AFP

It was a general perception among families that there was no help for their children, and they had to manage everything on their own. This perception was stronger among families of children with residual paralysis, and in fact, all families believed so. Also, they often did not know where they can go seek for help or what kind of help existed. Sometimes they tried to seek for help but ended up in vain, as the experience of these two mothers with ANMs show:

*"ANMs said there is no cure for this, take her to the city. I told them that I have taken her to city also to the government hospital. But they have also refused, so where do I go now. They still say take her there." (mother of 12 yr. old child with residual paralysis, onset at 2 yr. old)*

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<sup>ξ</sup> 'Health camp' in India refers to a one-day or a few-days programme set-up by the government or civil organizations for delivering healthcare or healthcare related services to its people free-of-cost. There are health camps from providing general medical check-ups and distributing hearing aids and mobility aids to education of women and children about personal hygiene and reproductive health.

*"We asked also ANMs for suggestions but they said that we are sent from there for giving drops and that is what we do." (uncle of 10 yr. old with residual paralysis, onset at 5 yr. old)*

What was more, even when they did have some information or have accessed services somewhere, things did not work rightly for them. There was an instance where low education level of the family hindered their action of going forth with what they were told.

*"They said write application. Now they have skills to do all that, what do we know? They had said to write application but then who will write..." (grandmother of 1.5 yr. old child with polio (P3), identified 6 m. before)*

Also, some things did not happen as they were told it would happen. One family said they were told they would get some financial help after the stool test, which they never got. Two families had experience of having their photos and names taken, but nothing happened afterwards.

*"I got my picture clicked; sent them to Pradhans; gave it in block office as well but nothing has happened so far... We went to Muzaffarnager with her and we came back at 12 - 1 am at night, after all these hardships." (father of 9 yr. old child with residual paralysis, onset at 1 m. after birth)*

There was just one case where they were provided crutches when they went to city. Otherwise, parents made crutches from wood and bought tricycle for their children on their own.

*"We bought him a cycle for Rs.2500. I used to cry and think when I had to carry him for nine months (to school); why should I wait for the government; I will buy it from my own money." (mother of 15 yr. old child with residual paralysis, onset at 1 yr. old)*

In contrast, some respondents among families whose children were diagnosed as non-polio and also showed recovery commented they got good support as illustrated in this quote:

*"I am satisfied with the 'polio people'(people who come for polio drops and who came to collect stools); they are doing a good job." (grandfather of 7 m. old child with non-polio AFP, identified 2m. before)*

## 4.5 Needs of children with polio and non-polio AFP

This last section displays themes around needs of children with AFP which emerged from all interviews. Focus was put on the needs of polio-affected children, for they were the ones who were in more need of help.

### ◆ Need of education

Many families expressed eagerly the need of education for their children with residual paralysis because they could not do the same as their parents or their siblings: i.e., doing labourer work. Their desire was to have their children educated so he or she would 'not be dependent on anybody', 'do something in life', and 'survive'. One mother stated:

*"That is must; only education will help him. If he can't do anything but if he will be educated, he may be successful in life." (mother of 3.5 yr. old child with polio (P1), identified 1 yr. 11m. before)*

Healthcare providers and key informants also suggested the need of education for these children, called it their 'basic need'.

### ◆ Transportation difficulties

Regardless of their strong feeling toward need of education, most children with residual paralysis were not attending school solely due to difficulties in transportation. Among the few who were attending, a lot of effort was needed in doing so; sometimes their mothers carried them to school or the child skidded along on his or her knees. On the other hand, even with those who could stand on their own feet but were still limping, their parents avoided sending them to school because they 'fall down' from time to time. Many were unable go out of their homes going to places, even to their relatives' house. This father pleaded for his daughter:

*"I just want that by whatever way she is just able to walk on her own. I don't need money. I just want that she should be able to walk on her own." (father of 10 yr. old child with residual paralysis, onset at 5-6 yr. old)*



**Photo 14:** 'His hands are dirty all the times since he walks on his hands. There is no strength in his legs.'

Need for some kind of transportation arrangements to school also was a theme emerged with healthcare providers and key informants. District level providers suggested that more NGO should come forward to

distribute mobility aids.

◆ **Medicine & Nutrition**

Need for sufficient medicine for these children was another common theme emerged among families.

*“Not even money that god looks after, but at least medicines should have been provided. It's government hospital, at least they should have given medicines.” (mother of 1.5 yr. old child with polio (P3), identified 6 m. before)*

Several PHC doctors and ANMs made a similar suggestion. In addition, some noted a need for improvement in the children's nutrition status.

◆ **Expectations from the government**

Expectations from the government were heard from many places. A number of families held a perception that the government should offer more help and pay more attention to the problems of children and their families when the children were affected by polio. One father made a statement on what the government's role should be:

*“If somebody is affected by polio, government should act as a shield. In case people are not capable of managing on their own, then they should be supported by the government.” (father of 12 yr. old child with residual paralysis, onset at 3 yr. old)*

Another father gave a reason behind to why they should be helped:

*“Government should help; when government is spending so much money for polio. Gives drops to so many children, going in villages, gives vehicles for it; government should work more rigorously. Something must be done or show them to a good government hospital. Then only one knows whether polio is getting cured or not.” (father of 3.5 yr. old child with residual paralysis, onset at 2 yr. old)*

Expectations from healthcare providers and key informants were also given to the government in helping polio-affected children by taking measures in fulfilling their needs in education, transportation, and healthcare. Moreover, some key informants indicated a necessity of looking into children who were classified as non-polio AFP, but if they were still classified as AFP under the system, they should be taken care of. One academic suggested:

*"See for them, any paralysis is polio. Ordinary people, why should I make the difference that this is due to poliovirus, and this is not due to poliovirus. My child is affected, my child is affected. I feel that if I have given that dose, that two drops, why should my child get polio? ...Every child with AFP needed to be suitably compensated as well as rehabilitated, irrespective of polio cases or non-polio cases. That should be the Government's responsibility." (Academic)*

◆ **No expectation**

On the other hand, some families expressed no expectation not only from the government, but more generally from anywhere due to their previous experiences of not getting any help. This made them indifferent, and they were unable to come up with their own needs or suggestions. Underneath was this belief that they were poor and poor people never get any help.

*We didn't get anything. Who gives to poor people? (grandmother of 3 yr. old child with polio (P1), identified 1 yr. 9m. before)*

*What can we say; government will do as they like, what can we say. (father of 9 yr. old child with residual paralysis, onset at 1 m. after birth )*

*The government doesn't help, so neither we ask for any support from the government. (father of 2 yr. old child with non-polio AFP, identified 3m. before)*



Photos 15-18: Children with polio and residual paralysis

In photo 15 and 16, the mothers were explaining how their children's legs were becoming thinner day by day. In photo 17, the boy stopped going to school of his paralysis, and girl in photo 18 said she wanted to go to school.

## Chapter 5: Discussion

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### **Introduction**

In this chapter, findings are put together and discussed within the context of the study and its limitations, along with information from other available literatures. Firstly, characteristics of children with polio and non-polio AFP are considered respectively followed by a section where it explores healthcare system of the study area. These information leads to the next section where the gap between families of children with AFP and healthcare providers are explored. Fourth section focuses on the needs of children with AFP, and lastly, limitation for this study is given.

### **5.1 Characteristics of children with AFP**

#### **5.1.1 Children diagnosed with poliomyelitis**

The study was able to include almost all polio cases for the past three years from the six high-risk blocks in the district and found these children surprisingly similar in their characteristics. Roberts (2004b) gave 'devastating poverty, rapid population growth, overcrowding, dismal baseline health, and lack of sanitation' (pp. 1964) as risk factors for polio, and these are consistent with other researchers and also with the pattern seen in this study (CDC, 2007; Grassly, 2006; etc.). Many polio-affected children included in this study came from marginalised caste and Muslim families who, in India, are known to be the poorest of the poor (Das, 2008)—also informal conversation with co-researchers, local NGO, and community members supported this view. Most families of these children were living with livestock, sometimes keeping them very close to their source of water, and flies were everywhere. Families often had many children, up to nine at times, and several relatives were living together in one house which made their living condition worse. Although number of children included in the study was limited, their characteristics were consistent with the information given by healthcare providers who were familiar with the area.

It was well known among the study's respondents, also documented in many literatures, that a few years back Muslim families were resisting giving polio drops to their children because there were rumours it would cause infertility in children (Dasgputa, 2007; Kishore, 2003; etc.). Many literatures at that time suggested this to be one of the biggest reasons behind for the high incidence of polio among the Muslims; that they were not taking oral polio vaccines (OPV) (CDC, 2002; Roberts, 2004b). Findings were made in this study that resistance due to these rumours has gone down, and Muslim mothers in FGDs were accepting 'polio drops'. Also, all polio-affected children in the study were taking more than 10 doses; still, they have not been effective for them. Many similar cases are now being reported by other studies

(Grassly, 2007; Arora, 2007).

Various explanations are put forward for this phenomenon by many researchers including: (1) less potency of OPV<sup>π</sup>, (2) failure to maintain 'cold-chain'<sup>σ</sup>, (3) non-polio entero-viruses interfering seroconversion<sup>ξ</sup>, (4) pockets of unimmunized children allowing continued circulation of wild poliovirus (WPV), (5) high prevalence of diarrhoeal diseases which could 'wash away' the vaccine before it is taken up in children's body, (6) poor nutrition and immunity of children, and (7) very low uptake of routine immunization (Mittal, 2007; Grassly, 2007; Kishore, 2003; etc.).

Providing support and insights into these explanations are beyond the scope of this study. However, some characteristics listed here do correspond to those of the polio-affected children in this study. Families named diarrhoea as the most common illnesses among their children. Imagining from their everyday meal, nutritional status seemed to be poor among these children, which characteristic also mentioned by healthcare providers. It is known the nutritious level in Uttar Pradesh is very low, and percentage of children under 3 years old who are underweight is estimated to be around 47.3% (Gol-CBHI, 2008). Uptake of routine immunization was also very poor among children in the study. OPV doses given through routine immunization are regarded to be more effective than given through SIAs as described before, and this may have impacted on their disease (Arita, 2006; IAP-PEC, 2008).

This study highlighted another characteristic of polio-affected children, which was low education level of parents. This may have played an important role in determining the uptake of routine immunization. In the study, many parents reported not taking their children for routine immunization because they perceived 'polio drops' was for every disease. Lack of education may lead to these kinds of misconceptions, and is generally known there are associations between vaccine uptake and education level of parents, especially of mothers. According to Buor's study (2003) examining the impact of mothers' education on childhood immunization status in Ghana, 86.7% of mothers with secondary education or above immunized their child, whereas for mothers without formal education, this was only 42.2%. Thus, education levels of parents may well have been one of the key reasons for the poor routine immunization uptake.

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<sup>π</sup>This was discussed in the Literature Review chapter, that seroconversion for OPV is limited, especially in the context of Uttar Pradesh, not much is known about its effectiveness; it seems to differ from other places. (Grassly, 2007)

<sup>σ</sup>OPV needs to be stored in a cool place in order to maintain its effectiveness because it is made from live attenuated virus.

<sup>ξ</sup> seroconversion: state in which antibodies to microorganisms are developed successfully in the blood serum, or in another words protection against that microorganisms is successfully established; when there are similar microorganisms, this process can be interfered

### **5.1.2 Children diagnosed with non-polio AFP; why pay attention to these children?**

Characteristics of children with non-polio AFP have not been looked at before. There were also only nine children included in the study, so their characteristics can not be discussed from just this study alone. However, it is important to note that many of them came from the poorer section of the society similar to the polio cases, and findings from this study suggested they were experiencing the same difficulties in getting healthcare. Paralysis may have been from other reasons, but for the families, every paralysis meant 'polio'.

Another reason for the need in paying more attention to these cases classified as non-polio AFP is because there still remain possibilities of these children to have been infected by either from wild poliovirus or from vaccine polio strain as already explained earlier; non-presence of wild poliovirus in stool may have lead to misclassification, or attenuated vaccine virus may have again became virulent and caused vaccine-associated poliomyelitis. These children may develop residual paralysis, and would be in need of long-term care. It is a known fact that there are residual paralysis cases among non-polio AFP. Puliye (2007) presented the data obtained from NPSP that of the 10,055 cases of non-polio AFP reported in Uttar Pradesh in 2006, 2,553 were followed up and 898 were found to have residual paralysis. Also in this study, one case of non-polio AFP was found to have residual paralysis after four months of onset.

Known AFP cases are increasing substantially in recent years as shown in Literature Review chapter (Table 3). Despite this, not much is known about them. Further study is needed in this area. It is important to understand what kind of characteristics they have, to understand the underlying disease among them and also to provide them equitable healthcare services.

## **5.2 Factors shaping healthcare experienced by the community**

### **5.2.1 Experiences and perceptions of community vs. healthcare providers**

This study found that people preferred seeking healthcare from private hospitals to government hospitals. Negative perceptions created by negative experiences at government hospitals seemed to have created this behaviour. However, there were reasons from healthcare provider's side which would explain as to why they were facing such experiences.

In the study, mothers in FGDs complained that they did not get good medicine, and that they had to buy medicine from pharmacies many times when they went to government hospitals. Taking doctors' position, they had to prescribe medicines for outside because they did not have specific medicine they wanted to prescribe in hospital or simply ran out of stock. Because they were supplied by the government, they did

not have control over supplies.

Many doctors suggested they were lacking in manpower, which sometimes made the necessity in making referrals to other hospitals, especially when a specialist's care was needed. This lack of manpower could have been a factor shaping their attitudes toward the patients, which people felt to be lacking attention and concern. The study also found that referrals had to be made sometimes because infrastructure was not in the hospitals for more specialized exams and treatments.

To understand this situation, it is important to recognize how Uttar Pradesh is still experiencing its early transition stage in terms of health system as indicated by Peters (2003). Ramani et al. have pointed out public health infrastructure is far from satisfactory in poorer states as the availability of services is constrained by '(1) non-availability of staff, (2) weak referral system, (3) recurrent funding shortfalls, (4) lack of accountability for quality of care, and (5) poor logistics management of supply of medicines and drugs' (2006; pp. 564). Access to services is an equally important determinant in meeting the healthcare needs of people especially in rural areas, but they are not being met having minimal or none public transport between PHCs/CHCs to the district/health hospitals (Ramani, 2006); which the same voices were heard from the people in this study. Many also mentioned how 'poor' do not get anything. This also was a particular concern made by Peters (2002) that 'pro-rich' distribution of public resources is exercised in Uttar Pradesh. Due to these factors, health status of the state is below average compared to many others (APPENDIX 1).

### **5.2.2 Effects from the Pulse Polio Programme**

This study indicated that the Pulse Polio Programme was adding an extra burden to this poor health system by having much resource put in, especially human resources. Though the programme itself was going on successfully as many healthcare providers highlighted, they all agreed on their increased workload. This led to more referrals to other hospitals for patients as discussed above. It also took part in developing people's impression that government doctors were not present in hospitals many times; which kept them from going.

Other researchers have also expressed concerns that there is significant opportunity cost associated with the Pulse Polio Programme when frontline healthcare providers were taken away from their other work to focus on NIDs (Taylor, 1997). On the other hand, Loevinsohn et al. (2002) introduced a WHO commissioned study in which it stated that poor healthcare deliveries depended on staff productivity, and not on polio eradication activities. However, this study was done in the Lao People's Democratic Republic, Nepal, and Tanzania where the estimated work time consumed for polio eradication was 12 days per year; where in this study's context, the health workers calculated the work taken up by polio activities to be

around 15 days per month. Also having shortages in human resources, it is likely the Pulse Polio Programme was having a substantial impact on the healthcare delivery of the area.

The study further found that many healthcare providers perceived the Pulse Polio Programme was hampering routine immunization to some extent by the workload put into this programme. Effects of the Pulse Polio Programme on routine immunization were also discussed in many literatures. Rapid appraisal by UNICEF evaluating relations between the Pulse Polio Programme and routine immunization services, also introduced in Loevinsohn's study (2002), indicated the 'missed opportunities' for promoting routine immunization created by the Pulse Polio Programme; such opportunities included coordinating planning activities, training sessions, and cold chain vaccine management.

The study also found the Pulse Polio Programme's influence on community's behaviour toward routine immunization from its house-to-house strategy. The 'booth coverage'<sup>ξ</sup> for OPV in the area was not reaching 50% (CORE, 2008), and some healthcare providers in the study suggested mothers were not coming out for routine immunization because they were now accustomed to being given 'polio drops' at their homes. This concern was already made in Arora's qualitative study done back in 1999 assessing the programme that people 'might come to expect other health services to be delivered in a similar house-to-house manner' (Loevinsohn, 2002). In addition, certain groups of mothers in the study were having misconception about the 'polio drops' that it was for every disease or having little awareness for routine immunization, which also was indicated by healthcare providers. This study found this tendency of belief and lack of awareness especially among mothers with poorer education. Hence, many earlier studies have indicated the influence of the Pulse Polio Programme on service delivery of routine immunization, but this study was able to find another impact of the programme. This impact was on the community itself, shaping people's mind-set and behaviour, which might have added a factor to the low routine immunization coverage of the area.

### **5.3 Gap in healthcare for children with AFP**

This study found experiences of families of children with AFP in using government hospitals were similar to those of other mothers. The treatments and care they received were inadequate having to buy medicines from outside many times, sometimes being asked go seek care from other hospitals, and little attention was paid for their affected children. Many complained only stool tests were done, and results which stated whether it was type P1 or P3 polio was given to them; when what all mattered to them was their children's illness. Most families were seeking treatments from private hospitals which incurred a considerable financial burden on them.

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<sup>ξ</sup> 'Booth coverage': children received OPV at the Booth set up on Sunday during SIAs

On the other hand, healthcare providers interviewed in the study believed the AFP Surveillance was beneficial to children, and many considered they were delivering a good service to them and their families. Doctors were sending stool samples according to guidelines, ANMs were reporting paralytic cases foremost to the nearest PHC, and reports were delivered to families at their houses. They were all performing and fulfilling their roles according to their positions.

The probable reasons behind for this gap relate to the nature of the AFP Surveillance and the poor quality of the health system in the area. AFP Surveillance is part of the Pulse Polio Programme which aims at global polio eradication, and its role is to detect children with WPV; so there will be no spread of the virus (Gol-WHO, 2008). Given this role under the programme, it has no responsibilities over treatment, care, or support. This was also clarified by one of its members through the study's interview. In places with adequate health infrastructure, just identifying children with AFP will not cause so many problems because subsequent treatment and care will most likely be taken up by the health system of the area. However, in a place like Uttar Pradesh where the quality of health system is poor, problem arises for the families of children with AFP because they do not have adequate places to seek for treatment and care afterwards. This results in an unbalanced provision of healthcare that on one side they are getting services for diagnosis, but on the other side, they are left without any treatment or care.

#### **5.4 Needs of children with AFP**

The study identified the following needs of children with AFP through interviews with their families, families of children with residual paralysis, healthcare providers, and key informants.

##### **◆ Medicine and nutritious diet**

Though medicines are symptomatic and supportive, there is a need for these medicines for children with polio. Secondary infections can be treated, and muscle pain in the affected-limbs can be relieved (Daniel, 1997). Families in the study talked about their needs for medicines free-of-cost. They were substantially burdened with cost of medicines for their children, and this expectation for support with medicine can well be understood.

Need of nutritious diet was suggested by several doctors in the study, and good nutrition is indeed vital for a competent clinical management in poliomyelitis. Boines (1953) has drew attention to the importance of nutrition status of poliomyelitis patients and stated that 'two dietary essentials, proteins and calories, are mutually indispensable' (pp. 358). Proteins are especially important in polio patients for two reasons: for development of immunity against the infection and also for effective tissue synthesis for preventing muscle atrophy (Boines, 1953). Though the study dates back several decades ago, what he stated stands as of

now. Recent studies refer to the role of protein in immunity as already an established fact (Chandra, 1996).

#### ◆ **Rehabilitation therapy**

Rehabilitation therapy for poliomyelitis includes physiotherapy, braces, corrective shoes, and corrective surgeries. Findings show free corrective surgeries for polio-disabled patients are now initiated by the Government of India though the study was not able to evaluate the accomplishment of this scheme. Nonetheless, corrective surgeries are only needed when a child reaches to a point when he or she develops deformity in later life.

In contrast, physiotherapy is a core treatment for polio-affected patients, and early ambulation is suggested by many physicians (Boines, 1953). However, most families in this study were unaware of physiotherapy despite a few that were told to do exercises at their homes but never were told how. This unawareness for physiotherapy was also found in Kishore's study (2003). This study also found lack of awareness among healthcare providers. When they were asked about treatment for polio patients, very few mentioned physiotherapy.

#### ◆ **Transportation facilities and mobility aids**

The study found many children with residual paralysis suffered from transportation difficulties, and many were unable to go outside of their houses because of not having any transportation means. This hindered their access to education also.

According to the government's policy, provision of access for people living with locomotor disabilities is ensured under the Persons with Disabilities Act, 1995 (GoI, MoSJ&E, 2008). However, it is documented by World Bank (2007) that this government's scheme is not reaching to those in need especially in the rural area and amongst the poor. Barriers to accessing to this public policy that this study was able to identify were: (1) lack of awareness of the provision of both the families and the healthcare providers, and (2) poor education of the families because the procedure for obtaining this certificate is complex, also requiring many written application forms (GoI-MoSJ&E, 2008; World Bank, 2007).

#### ◆ **Education**

Education was mentioned by many families in the study as their needs for the children to be independent in the future despite their paralysis. This importance of education was also stated in the World's Bank document (2007): 'education is critical to expanding the life prospects of people with disabilities' (World Bank, 2007). Also, free access to education for the disabled is ensured by the Government of India under the Persons with Disabilities Act, 1995 (GoI, MoSJ&E, 2008). However, in spite of families' strong desire

and universal standard principle, very few were attending school in the study. The study found transportation difficulties as the biggest barrier to education for these children.

◆ **Awareness and sufficient information**

As stated earlier, the study found awareness of both the families and the healthcare providers were lacking in what kind of treatments and services there were for children with AFP. There is a need for raising awareness and making information available for everyone in order to improve clinical management of AFP and to promote available services for these children.

### **5.5 Limitation of the study**

Generalizing the findings to other settings and to a wider population would only be possible to a certain extent because the study was conducted just in one district. Also, access to some information was limited including some patient information and other data which could have helped develop more insights into this study.

Still, focus of this study on healthcare for children with AFP is a theme which has never looked at before, and the study was able to highlight their experiences around what kind of healthcare they received and the reasons for their experiences.

## Chapter 6: Strategic options

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In this chapter, list of strategic options drawn from findings of this study are given.

### Strategic options to fulfil the needs of children with AFP

1. Medicines including antibiotics and analgesics should be provided free-of-cost for all children diagnosed with AFP according to their conditions. This should also include nutrition supplements for as long as paralysis persists, for both polio and non-polio, and till when they have grown old enough to be in no need of such aids. Taking into account these children's low socio-economic status, support with their nutrition should be considered as one of the priorities in their treatment.
2. It is essential to raise awareness of both the healthcare providers and the families of physiotherapy and moderate exercise for polio-affected children. Awareness raising among the healthcare providers including PHC doctors and ANMs can be done within the monthly training sessions for the Pulse Polio Programme.
3. Services offered at government hospitals should be expanded. PHCs should be supplied with adequate medicines, and capacity should be built in the District Hospitals to be able to assist the PHCs when they are incapable of certain services.
4. Referral system should be strengthened between PHCs to District Hospitals, and to rehabilitation services if there are any close by, so families would know where they could go seek for services. Transportation facilities should be established connecting PHCs and District Hospitals to promote families to utilize public services more.
5. Information for available benefits and social welfare services (e.g., existence of government policy, health camps) should be provided adequately to the families. Individuals who are in good position to inform and help the families would be: ANMs, ASHAs, Anganwadis, Block monitors of the National Polio Surveillance Project (NPSP)<sup>ξ</sup>, Block supervisors of the Pulse Polio Programme<sup>Ⓜ</sup>, private doctors, religious leaders, and Pradhans. Using the network established through the Pulse Polio Programme, especially the Social Mobilization network, these groups should be made aware of available services

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<sup>ξ</sup> Block monitors of NPSP: Most peripheral workers of NPSP who are involved in coordination across various sectors and monitors SIAs at block level.

<sup>Ⓜ</sup> Block supervisors of the Pulse Polio Programme: people selected from the community to supervise the programme; for example, teachers.

for paralytic children and provide the families with the information.

6. Action should be taken to ensure that children suffering with residual paralysis are able to obtain a physically handicapped certificate under the Persons with Disabilities Act. This will help them obtain transportation means and education. A person or organization, for example Block supervisors of the Pulse Polio Programme, ANMs, or Pradhans, should be given the responsibility in facilitating the process of certification including writing applications on behalf of them. Also, simplifying procedures for certificates should be considered, and one measure may be taken by accrediting qualified private doctors for certification.

### **Other strategic options drawn from the study's findings**

7. Further research into children with non-polio AFP is needed to understand their characteristics, and this may help understand the underlying diseases among them, including possibility of VAPP and missed cases of poliomyelitis from WPV. This study was able to find difficulties for these children and families in obtaining healthcare, but since there are so many of AFP cases in Uttar Pradesh, it is necessary to first understand who they are. This knowledge is necessary to provide further healthcare for them and to evaluate any unnecessary reported cases (e.g., AFP cases reported with indefinite symptoms, cause of AFP revealed few days after identification) to reduce the workload and cost of the services.
8. Information from this study and other researches suggest there is a need to enhance routine immunization among children of the area to prevent them from being affected by polio. The magnitude of the issue is big and is beyond this study's capacity to present detailed strategic options. However, lack of awareness of routine immunization among these parents was almost consistent in the study. Even though polio teams were trying to educate them while going house-to-house giving polio drops, this had not been effective among population with poorer education. More effective awareness raising measures should be considered, and the approach from both healthcare providers and from the community should be envisaged to improve routine immunization in the area.

## Chapter 7: Conclusions

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This study was able to uncover the realities faced by the children identified with AFP under the Pulse Polio Programme, a programme set up to achieve the goal of eradicating polio from India and from the world. The realities were: the children were the most vulnerable in society, confronted with overwhelming poverty. Poverty made them susceptible to polio and other diseases, as well as to the poor healthcare provision they received after onset of their disease.

Qualitative methods used in this study helped elucidate these valuable findings, and no other methods could have achieved the same. They enabled the researcher to look into the issue from all kinds of angles, from the families, from the healthcare providers, and from the key informants from the community to develop a holistic picture to what had happened to these children.

For improvement, it is necessary to pay attention to these children who are identified with AFP, who they are, and enhance their quality of life by providing them adequate healthcare. This is important not just for the benefit of these children, but also for the programme itself in moving toward eradication of polio. Improvements in general living conditions, healthcare, education, all are needed to have the disease eradicated, and these needs can be met more if there are better understanding of these children. Thus, integrated approach is needed, both from the government and from the international powers, if ever, this disease is going to be eradicated from the world.

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## Appendices

### -APPENDIX 1-

Table of selected health status outcomes in major Indian states from latest source

State	Population* <sup>1</sup> 2008	Infant mortality rate* <sup>2</sup>	Total fertility (Rural/Urban)	Childhood underweight %<-2SD)	Immunization (full)(%)* <sup>3</sup>	Immunization (polio)(%)* <sup>4</sup>
Uttar Pradesh	190.2	72	4.5/3.3	47.3	23.0	87.6
Andhra Pradesh	82.3	56	2.2/1.7	36.5	46.0	79.2
Assam	29.4	67	3.1/1.6	40.4	31.4	59.0
Bihar	93.6	60	4.4/3.2	58.4	32.8	82.4
Gujurat	56.6	53	3.1/2.3	47.4	45.2	65.3
Haryana	24.1	57	3.0/2.3	41.9	65.3	82.8
Karnataka	57.5	48	2.5/1.8	41.1	55.0	73.8
Kerala	33.8	15	1.7/1.7	28.8	75.3	83.1
Madhya Pradesh	68.7	74	4.0/2.5	60.3	40.3	75.6
Maharashtra	107.9	35	2.4/1.9	39.7	58.8	73.4
Orissa	39.6	73	2.7/1.7	44.0	51.8	65.1
Punjab	26.7	44	2.2/1.9	27.0	60.1	75.9
Rajasthan	64.5	67	4.0/2.7	44.0	26.5	65.2
Tamil Nadu	66.1	37	1.8/1.6	33.2	80.9	87.8
West Bengal	86.9	38	2.4/1.4	43.5	64.3	80.7
<b>INDIA</b>	<b>1144.7</b>	<b>57</b>	<b>3.2/2.1</b>	<b>45.9</b>	<b>43.5</b>	<b>78.2</b>

In blue are the epidemic states of polio: Uttar Pradesh and Bihar.

\*1 Population given per million \*2 Infant mortality rate: given per 1000 \*3 Children 12-23 months fully immunized (BCG, measles, and 3 doses each of polio/DPT) (%) \*4 Children 12-23 months who have received 3 doses of polio vaccine (%)

(Source: Gol-CBHI, 2008)

## -APPENDIX 2-

Table of characteristics of families who were unable to be included in the study

No.	Age of Notification	Sex	Stool Test Result	No. OPV (SIAs)	No. OPV (R)	Living Setting	Religion	Occupation	Memo
1	4 yr.	M	P3 Wild	33	0	Rural	Hindu	Labourer	Died
2	1 yr. 6m.	F	P3 Wild	9	0	Rural	Muslim	Tailor	Rejected
3	3 yr. 0m.	M	P3 Wild	15	0	Rural	Muslim	Labourer	Cannot find address
4	6 yr. 0m.	M	Negative	20-25	0	Rural	Muslim	-	Moved to different village

### -APPENDIX 3-

**Table of characteristics of families of children with residual paralysis**

No.	Age of child	Sex	Age of onset of paralysis	Religion	Education of parents	Occupation of parents	No. of children
1	11 yr. old	M	unknown	Hindu	illiterate	labourer	4
2	12-13 yr. old	F	1.5 yr. old	Hindu	illiterate	labourer	2
3	9 yr. old	F	2 or 2.5 yr. old	Hindu	2-3rd	labourer	5
4	3.5 yr. old	M	2 yr. old	Hindu	illiterate	-	6
5	9 yr. old	F	1 m. old	Hindu	illiterate	vegetable seller	7
6	8 yr. old	M	17 d. old	Hindu	-	labourer	6
7	12 yr. old	M	3 yr. old	Muslim	illiterate	labourer	7
8	14 yr. old	M	1 yr. old	Hindu	illiterate	children working as labourers	5
9	14 yr. old	M	2-3 m. old	Muslim	illiterate	father passed away	7
10	12-13 yr. old	F	2 yr. old	Muslim	Urdu	labourer	5
11	10 yr. old	M	7 m. old	Muslim	illiterate	labourer	6
12	6-7 yr. old & 11 yr.-old	M M	unknown unknown	Muslim	illiterate	labourer	3
13	10-12 yr. old	F	1 yr. old	Muslim	illiterate	labourer	4
14	12 yr. old	F	undnown	Muslim	illiterate	labourer	5
15	5 yr. old	M	immediately after birth	Muslim	illiterate	labourer	8
16	15 yr. old	M	1 yr. old	Muslim	illiterate	truck driver	5
17	6 yr. old	F	5 yr. old	Muslim	-	labourer	-
18	10 yr. old	F	5 yr. old	Muslim	illiterate	labourer	

## -APPENDIX 4-

### **Checklist for Semi-structured Interviews with THE PARENTS WITH ACUTE FLACCID PARALYSIS**

#### *TOPIC GUIDE:*

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#### Topic 1. Experience around the Usage of Health Facilities at the Time of Onset of the Disease (Patient History)

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- 1.1 What were the symptoms of your child when you first noticed something was wrong?  
[Probe: How did you first notice something was wrong with your child? How did you come to know about your child's disease?]
- 1.2 When was it?
- 1.3 Where did you take him/her to? What doctor?
- 1.4 Why did you take her to [the place mentioned in 1.3]?
- 1.5 What happened after that?  
[Probe: What kind of exams did you have to go through? What kind of treatment did you get? Did you have to go somewhere else? etc.]
- 1.6 What information did doctors give you for your child's disease?
- 1.7 Did your child do a stool test?
- 1.8 Where did your child have the stool test done? At hospital or somebody come to your house?
- 1.9 What kind of treatment, support, or care did you get after the stool test from the people visiting you at your house [ANMs, doctors]?
- 1.10 What information did they provide you with polio about the illness [regarding the characteristic of the disease, e.g., prognosis]?
- 1.11 Also, what information did they provide you regarding treatment, support, and care of the disease [polio]?
- 1.12 What happened *when* the result of the stool test came?  
[Did some one explain the result to you? If yes, what kind of explanation did you get? If no, why didn't you get the result?]
- 1.13 What happened *after* you got the result for the stool test?  
[Were you still visited by the doctors and ANMs?]
- 1.14 Were you visited after 2 months time after you went to hospital for the first time? (60-day follow-up to see residual paralysis)
- 1.15 What do you think of these services by the government they've got for your child?

---

**Topic 2. Treatment, support & care**

---

- 2.1 Where are you getting treatment / support / care for your child? If not getting any, then why?
- 2.2 What kind of treatment / support / care?
- 2.3 Why did you choose to get the service from [answer of 2.1]?
- 2.4 What were your difficulties getting treatment, support, and care at the time of onset of polio?  
[e.g., cost, transportation, etc.]
- 2.5 What are your difficulties now getting treatment, support, and care for your child?
- 2.6 What did / do you feel about the cost of treatment?
- 2.7 How is the treatment cost affecting your family?

---

**Topic 3. Difficulties with the symptom of the child**

---

- 3.1 How is your child now?  
[Probe: recovered, symptoms still remaining (e.g., cannot sit up, cannot walk)?]
- 3.2 What are your challenges and difficulties of looking after this child? Please share actual experiences.

---

**Topic 4. Needs and suggestions for the future**

---

- 4.1 What kind of information should have been helpful for you at the time when you were visiting hospitals? Also for now and for the future?
- 4.2 What kind of help (support and care) did you needed or think situation would have been better if you had?
- 4.3 What are your suggestions for support and care for a child like yours?
- 4.4 What are your suggestions for the government?

---

**Topic 5. Experience and Understanding of Polio and Polio Vaccine**

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- 5.1 I have come to know that you had been giving polio drops to your child. How many times your children has gone through this drop?
- 5.2 Did you ask the doctor why your child got polio despite you giving the drops? What did they tell you?
- 5.3 In what way have your views of the polio drops changed after your child having the disease?

---

**Topic 6. Experience with the Routine Immunization**

---

- 6.1 Have you been going through immunization other than polio? If yes, what? If no, why not?
- 6.2 What do you think are the differences between the polio drops and other immunization?  
[Probe: access is difficult, cost, lack of information, etc.]

---

**Topic 7. Experience and Perceptions around Child Health and Healthcare**

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- 7.1 Please explain your daily meal. (How many times? What do you eat?)

7.2 Do your child get sick often? If yes, what kind of disease?

7.3 What kind of treatment or support / care do they get for this? From where?

7.4 Do you see any differences between the support you are getting for paralysis and for other diseases?

What are your thoughts around this?

7.5 What kind of services do you need for your child?

7.6 How do you think health services for children in your area can be improved?

## -APPENDIX 5-

### **Checklist for Semi-structured Interviews with THE HEALTHCARE PROVIDERS**

#### *TOPIC GUIDE :*

---

#### **Topic 1. Perceptions around Child Health and Healthcare**

---

- 1.1 How is the health condition of children in the area?
  - 1.2 What kind of disease is commonly seen among children in your clinic?
  - 1.3 What do you think are the priorities taken by the community regarding child health?
  - 1.4 What do you think of the health system in the area? How is it affecting child health?
- What are the things that you think should be done to improve the health condition of children in your area?

---

#### **Topic 2. Perceptions and Experiences with Vaccinating Children**

---

- 2.1 What is your perception on the polio drops?
- 2.2 Do people come to your clinic for polio drops?
- 2.3 What information do you give to mothers when you are giving the children the polio drops?
- 2.4 Do you face any resistance from mothers? If yes, who resist and for what reasons?
- 2.5 How do you persuade mothers who resist to take the polio drops?
- 2.6 Have you seen any changes in mothers' view/perception to the polio drops over the years?
- 2.7 What impact do you think the polio drops are having on the community?
- 2.8 I hear that many drops, sometimes as much as twice a month is given to a child, what is your view on this?

---

#### **Topic 3. Perceptions and Experiences with the Pulse Polio Programme**

---

- 3.1 Are you satisfied with the government's programme regarding eradication of polio? Why or why not?
- 3.2 What is and how do you see the workload of polio immunization in your clinic/hospital?
- 3.3 What challenges do you face in taking part in this programme?
- 3.4 Is it affecting your other service areas? If yes, how?
- 3.5 Do you feel pressurized for this particular service delivery? If yes, in what way?
- 3.6 What kind of support are you getting from the government regarding this polio immunization?
- 3.7 Do you see any changes in this government's programme recently? If yes, how?
- 3.8 How do you think of the quality of ANMs and ASHAs? How is the quality of their work?
- 3.9 What are the drawbacks and improvements of this programme?
- 3.10 Are you aware of the role played by the international organizations regarding the Pulse Polio Programme?

- 3.11 What impact they have on this programme?
- 3.12 Do you think of this overemphasis taken by the government has influenced the other sector of health care?
- 3.13 What should the government do to improve this programme in relation to other health care?

---

**Topic 4. Perceptions and Experiences with the Routine Immunization**

---

- 4.1 How is routine immunization in the area? How is the coverage?
- 4.2 If it is not good, what are the reasons behind?
- 4.3 How do you think it can be improved?

---

**Topic 5. Experience with the AFP Cases including Poliomyelitis**

---

- 5.1 How is a child diagnosed as acute flaccid paralysis?
- 5.2 What happens to a child when you give a diagnosis as AFP?
- 5.3 Do you have any AFP cases among your patients? If yes, is there a trend to what kind of family they come from?
- 5.4 What kind of treatment or care are they getting?
- 5.5 Do you know any polio cases in the community?
- 5.6 Do you know what kind of treatment or care they are getting?
- 5.7 What do you think are the needs of these children?
- 5.8 What do you think should be done for them by the government?

## **-APPENDIX 6-**

### **Checklist for Focus Group Discussions with FAMILY MEMBERS OF A CHILD UNDER 5-YEARS**

#### *TOPIC GUIDE:*

---

#### **Topic 1. Perceptions around Child Health and Healthcare**

---

- 1.1 When child is sick, where do you go?
  - 1.2 What kind of facility do you have?
  - 1.3 Do you have to pay to go to the facility?
  - 1.4 What is your experience?
  - 1.5 What kind of disease is mostly seen in your village?
  - 1.6 When your child gets sick, is it taken as much attention as polio?
- 

#### **Topic 2. Understanding of Polio and Polio Vaccine**

---

- 2.1 What is your understanding of polio?
  - 2.2 How did you come to know about polio?
  - 2.3 What kind of treatment they go through if a child is suffering from polio?
  - 2.4 Do you know about polio drops?
  - 2.5 Why is it given to children?
  - 2.6 How many times your children have gone through this drop?
  - 2.7 What is the impact of polio drop on your child?
- 

#### **Topic 3. Experience with the Pulse Polio Programme**

---

- 3.1 How you come to know about the Pulse Polio Programme?
- 3.2 Have you given your children polio drops?
- 3.3 What were your experiences with giving your children polio drops?
- 3.4 Will somebody share their experience?
- 3.5 What do your family and friends say about polio drops?
- 3.6 How do you think the Pulse Polio Programme is going on?
- 3.7 What is the impact of the Pulse Polio Programme in your village?
- 3.8 How do you think the polio drops should be given to your children? (Where? By whom? When? How?)

**-APPENDIX 7-**

**AFP Case Investigation Form**

## **-APPENDIX 8-**

### **Coding framework for THE PARENTS WITH ACUTE FLACCID PARALYSIS**

- 1 Personal details**
- 2 Patient History (Onset of paralysis)**
- 3 Experience of using health facilities at the time of onset of paralysis**
  - Health seeking behaviour
  - Public facilities
  - Experience of using public facilities
  - Reasons for not using public facilities
  - People visiting homes
  - Experience of using private practice facilities
  - Other issues
- 4 Examination**
  - Stool test
  - Other exams
- 5 Treatment, support, and care**
  - Public facilities
  - Public facilities not giving treatment
  - Private practice facilities
  - Family members
- 6 Information given by service providers**
  - Public service providers
  - Private service providers
  - Reasons for the disease (despite taking polio drops)
- 7 Support obtained**
  - Government
  - Community
- 8 Cost**
- 9 Present status of the child**
  - Symptom
  - Difficulties with the symptom
  - Other health problems

**10 Worries, needs and suggestions**

Worries

Needs and suggestions

No expectation

**11 Education**

Importance

What is needed

**12 Difficulties of the family**

Illiteracy of parents

Poverty

Other issues

**13 Experience and perceptions of polio drops**

Experience of giving polio drops to the affected child

Effect of the disease on giving polio drops to other children

Acceptance of polio drops

Negative perceptions of polio drops

Government & Polio

Rumour

Change: past & present

Awareness

**14 Routine immunization**

Experience of routine immunization

Awareness of routine immunization

**15 Other key issues (not covered above)**

Experience with public health facilities for other things

Overall background of the society

Other issues

## **-APPENDIX 9-**

### **Coding framework for THE HEALTHCARE PROVIDERS**

#### **1 Personal details**

#### **2 Experience and perception of dealing with AFP cases**

Cases

Characteristics & background of polio cases

Process of diagnosis

Treatment

Follow-up

Support & care

Information given to family

Benefits for the child of diagnosed under the Pulse Polio Programme

Suggestions

Other issues

#### **3 Role in the Pulse Polio Programme**

Frontline health provider

Government

International organizations

Coordination among the providers

#### **4 Perception of polio vaccine**

#### **5 Perception of the Pulse Polio Programme**

Current situation

Reasons behind for the current situation

Change: past & present

Challenges in carrying out the programme

Determinants of polio vaccine uptake

Workload of the programme

Impact / Effect of the programme

Community

Other health and healthcare services

Suggestions for improvement

Future of the programme

Other issues

**6 Understanding of the community's perception on the Pulse Polio Programme by the providers**

Awareness

Acceptance

Resistance

Rumours

Other reasons behind

How providers convince

Change: past & present

Other issues

**7 Perception of the Routine Immunization**

Current situation

Comparison with the Pulse Polio Programme

Change: past & present

Challenges in carrying out the programme

Suggestions for improvement

Future of the programme

Other issues

**8 Perception of the general situation in the area**

Common diseases of children

Health and healthcare provision

Programmes running

Challenges & difficulties

Needs

Suggestions for improvement

Other issues

**9 Other key issues**

## -APPENDIX 10-

### **Coding framework for THE FOCUS GROUP DISCUSSIONS**

#### **1 Personal Information**

#### **2 Experience and perceptions of polio drops**

Experience and knowledge of giving polio drops to children

Acceptance of polio drops

Negative perceptions of polio drops

Use of force

Abuse to health providers

Government & polio

Rumour

Change: past & present

Awareness

Source of information

Knowledge of polio as a disease

#### **3 Routine immunization**

Experience and knowledge of giving RI

Not-giving

Not sure

Awareness

Source of information

#### **4 Experience of using health facilities**

Health seeking behaviour

Government hospitals

Experience

Reasons for not using public facilities

Private practice

Village doctor

Other issues

#### **5 Common disease**

#### **6 Difficulties**

Illiteracy

Poverty

- Other issues
- 7 **Cost of treatment**
- 8 **Education**
- 9 **Needs and suggestions**
- 10 **Other key issues**

**-APPENDIX 11-**

**INFORMED CONSENT SHEET FOR FAMILIES OF CHILDREN WITH AFP**  
**(English)**

My name is Rie Roselyne Yotsu, and I come from Japan. I am a medical doctor by profession, but currently studying at the Liverpool School of Tropical Medicine in United Kingdom. I am here to do a research on the Pulse Polio Immunization programmes which much emphasis is put upon in this region. I am aiming to gain deeper understanding of community's views and feelings toward the programmes and also to investigate on their impacts on the community. This study may help generate information that can help inform national and international programme managers on better programme strategies and on other health needs of the community. Indian non-governmental organization called the Centre for Health and Social Justice are collaborating with me in the research.

This is my research assistant. (name) is Indian. We would like to invite you to be part of this research. We will ask you about your experience and perceptions of the pulse polio programmes. Any information that will be discussed will be treated in strict confidence and will not be linked to you by name or any identity. If you accept, we would like to record our discussion because it is difficult for us to remember everything that will be discussed. We will also be taking some notes for the same reason.

Your participation in the study will involve an interview of approximately about 45 minutes to 1 hour. Time and place will be selected to be convenient for you.

You will not be obligated to answer any questions if you do not want to, and you have the right to withdraw from the research at any moment if you want to; there would be no negative consequences. The result of this study may not benefit you directly but you would contribute to the health service of the community through helping to generate information that may be used by the programme managers of polio immunization programmes.

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact the following : [name, address/telephone number/e-mail].

Thank you for your help.

If you are willing to participate, please sign below:

Participant name.....

Participant signature.....

Date .....

Address.....

Verbal consent yes..... no.....

*If verbal consent:*

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual .....has given consent freely.

Witness name.....

Witness signature.....

Date.....

-APPENDIX 12-

**INFORMED CONSENT SHEET FOR FAMILIES OF CHILDREN WITH AFP**  
**(Hindi)**