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From Research to Policy to Programme: Success Story of Seven State Iodine Deficiency Disorders (IDD) Survey in India

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SUMMARY

Iodine Deficiency Disorders (IDD) constitute the single largest cause of preventable brain damage worldwide. In India the entire population is prone to IDD due to deficiency of iodine in the soil of the subcontinent and consequently the food derived from it. Of these, an estimated 350 million people are at higher risk of IDDs as they consume salt with inadequate iodine. Every year nine million pregnant women and eight million newborns are at risk of IDD in India.

On September 13, 2000, the Government of India lifted the ban at the national level on the sale of non-iodized salt (India Gazette 2000). Scientists, civil society, international agencies and other stakeholders joined ranks to fight against this retrograde step by the government of India. The four pronged approach to fight the removal of ban on non-iodized salt comprised of writing advocacy documents, meeting with stakeholders, media campaign and tracking of Universal Salt Iodization (USI) in states by state iodine status surveys.

But effective advocacy and media campaign were hampered by lack of scientific data substantiating the magnitude of Iodine Deficiency disorders (IDD) in India. To address this lacuna, state level Iodine status surveys were planned in seven states of India and were executed over next five years in collaboration with various national and international stakeholders.

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State level IDD surveys were carried out in seven states (Kerala, Tamil Nadu, Orissa, Rajasthan, Bihar, Goa and Jharkhand) from 2000 to 2006 by International Council for Control of Iodine Deficiency Disorders (ICCIDD) in collaboration with state medical colleges, Micronutrient Initiative (MI) and UNICEF. The surveys were carried as per the recommended guidelines of WHO/UNICEF/ICCIDD and used 30 cluster into 40 children sampling methodology. Children in the age group of 6-12 years, women in the household, retail shop keepers and other community stakeholders constituted the study population. All three indicators viz. Total Goiter Rate (TGR), Urinary Iodine (UI) concentration and iodine content of salt (household and retail shop) were studied. TGR ranged from 0.9% in Jharkhand to 14.7% in Goa. The median urinary iodine excretion ranged from 76 μg/L in Goa to 173.2 μg/L in Jharkhand. The household level consumption of adequately iodized salt (≥ 15 ppm) ranged from 18.2% in Tamil Nadu to 91.9% in Goa. These state level IDD surveys are the only sub-national (state) level IDD surveys in India where all three indicators viz. iodized salt coverage, urinary iodine and TGR were assessed concurrently.

These surveys provided valuable reliable scientific data to back up the need of urgency to re-instate the ban and aided in convincing wider scientific community and policy makers regarding the need for the same. These surveys also aided in capacity building at state level which will provide necessary impetus to sustain USI. The ban on sale of non-iodized salt was finally re-instated in May, 2005.

Purpose of the study : To understand the complex policy environment in which National Health Programmes in India are operating.

Basic Procedures : A case study approach applying the criteria of policy formulation and policy implementation to National Iodine Deficiency Disorders Control Programme (NIDDCP).

Main Findings : The major limiting factor in the implementation of NIDDCP was that the community perceptions about IDD and iodized salt and their interests and beliefs *(Values)* were not explicitly considered as part of the implementation process. Addressing the values through sustained advocacy, development of partnerships among stakeholders, supply and demand side interventions and more research based on the programme needs helped in achieving sustainability in elimination of IDD.

Conclusion : In formulating National Health Programmes in a policy environment, scientific inputs, political will and institutional structure for decision making are

necessary but not sufficient. Pro-active recognition *values* of key stakeholders, continuous and dynamic generation of scientific information and development of partnerships are critical for sustainability of the National Health Programmes.

Keywords : Policy, Values, National Iodine Deficiency Disorders Control Programme, Sustainability, India.

INTRODUCTION

Every government has a responsibility to protect the health of its population. Governments achieve this by formulation of policy and programmes. Policies and programmes are formulated in the light of available evidence regarding the public health importance of a health problem. Formulation of policy and programmes based on available evidence is an iterative process (1). Generation of evidence about problem and intervention leads to formulation of a policy and that translates into programme through development of institutional structures and mechanisms of monitoring and surveillance. Results of evaluation of programme determine future research agenda. However, establishing an effective and efficient programme is a continuing and a complex challenge and is subject to many competing factors besides the science of it.

There have been many examples of successful implementation of National Health Programmes in India and other developing countries. But one of the major stumbling blocks has been ensuring "sustainability" of the programmes once the pre-set goals and targets have been achieved after initial intensive phase. The challenges for ensuring "sustainability" can be much more complex and daunting as compared to the program initiation phase.

The dynamic evolution of National Iodine Deficiency Disorders Control Programme (NIDDCP) in India provides a unique opportunity to study the interaction between research, policy, programme and decision making process and to identify solutions for the future. This also helps in understanding the complex policy environment in which National Health Programmes operate and to identify key enabling and impeding factors. The development over last decade of NIDDCP provides excellent opportunities to understand the issues related to "ensuring" sustainability of the national health programs.

Case study :

Problem Statement :

Iodine Deficiency Disorders (IDD) is the most common cause of preventable irreversible brain damage worldwide. IDD comprise of a spectrum

of diseases including goiter, cretinism, hypothyroidism, brain damage, abortion, still birth, mental retardation, psychomotor defects and hearing and speech impairment. Iodine Deficiency causes a reduction of 13.5 IQ points in children and may lead to major learning disabilities (2). Globally 1.88 billion people are at risk of iodine deficiency disorders due to insufficient iodine intake (3). In India, Iodine Deficiency Disorder is endemic, defined as prevalence of more than 10%, in 303 districts out of 365 districts surveyed (4). An estimated 350 million people are at risk of IDD in India.

Intervention :

Universal Salt Iodization is considered as cornerstone in the control of iodine deficiency disorders. In 1994, a special session of the WHO and UNICEF Joint Committee on Health Policy recommended Universal Salt Iodization as a safe, cost-effective, and sustainable strategy to ensure sufficient intake of iodine by all individuals (5). Salt iodization which costs 0.05 US$ per persons per year and has a benefit- cost ratio of 81 has been identified as a priority area for targeting hunger and malnutrition by Copenhagen Consensus Statement 2012 (6).

In India, effectiveness of salt iodization to control Iodine Deficiency Disorder was established in a landmark study in the Kangra valley in Himachal Pradesh from 1956 to 1972 (7). This lead to establishment of National Goiter Control Programme (NGCP) in 1962 (8). Promotion of consumption of iodized salt in the endemic areas was one of the key features of NGCP. In the face of emerging evidences, the programme was modified and renamed as National Iodine Deficiency Disorders Control Programme (NIDDCP) in 1992. In the same year, pursuant to the advice of Central Committee for Food Standards, Government of India advised all states to ensure mandatory salt iodization for direct human consumption under the provisions of Prevention of Food Adulteration (PFA) Act, 1954. For the sake of uniformity in implementation of legislation throughout the country, further amendment was done in PFA Act in 1997 to ban sale of non-iodized salt for direct human consumption throughout the country (9). However, in year 2000, ban on sale of non-iodized salt for direct human consumption was lifted (10), which was reinstated again in 2005 after sustained advocacy (11). Recently, in year 2011, the Supreme Court of India and a committee established under its direction upheld the scientific basis of mandatory salt iodization for control of Iodine Deficiency Disorders (12). In the same year, regulations under Food Safety and Standards Act, 2006, which has replaced PFA Act 1954, were notified banning sale of non-iodized salt for direct human consumption (13).

Control of Iodine Deficiency Disorders in India can be divided into four phases:

Phase 1: Scientific research leading to program (1956-1983) :

Based on the success of the Kangra Valley study, the Government of India established the National Goiter Control Program (NGCP) in 1962 at the end of the second Five-Year Plan (8). The NGCP was focused on highly endemic areas like Himalayan goiter belt. During this period only 12 salt iodization plants were established with actual production of 0.2 million tons/year, which was estimated to be 15% of the need. Due to area specific approach and recognition of IDD as a mild cosmetic problem restricted to a particular region, NGCP remained a low priority health programme.

Phase 2: Influencing institutional decision making leading to policy change (1983-2000) :

During this phase new scientific evidence that emerged both from across the world and from India, showed significant impact of iodine deficiency on early brain development, cognition and learning abilities of children (14, 15, 16). Evidence also emerged regarding very high prevalence of neonatal hypothyroidism in some parts of the country (17). New evidence also established that the whole country is prone to IDD (18). This led to programme being modified and renamed as National Iodine Deficiency Disorders Control Programme in 1992 with increased focus on Universal Salt Iodization.

The linking of iodine deficiency with problems in learning and its consequent effect on achievement of the goal of "Education for All" convinced the political leadership of the critical importance of the problem and helped in securing the high level of political commitment. In 1983 in the Annual Meeting of Central Council of Health, it was decided that all edible salt in India would be iodised by year 1992 and the private sector was allowed to set up salt iodization units (19). After sustained advocacy, Government of India notified a national level ban on sale of non-iodised edible salt in year 1997 (9). These measures caused an increase in production of iodized salt from 0.2 million tons in 1986 to 4.4 million tons in 2000 (20). This also led to an increase household consumption in iodized salt with 49% households consuming adequately iodized salt ($\geq$ 15 Parts per million (PPM) (21).

Phase 3: "Values" affecting program and policy (2000-2005) :

The ban on the sale of non-iodized salt or human consumption was lifted in September 2000 (10). Some of the factors responsible for this action could have been price differential in iodized and non-iodized salt, IDD being viewed as a problem affecting only a small section of the society, difficulties faced by salt producers under Prevention of Food Adulteration Act, 1954, politics and economics of liberalization in terms of the programme being labeled as run by multinational aid agencies and companies

and principles of choice. It was reasoned that "Matters of public health should be left to the informed choice, and not enforced through compulsion". This led to a decline in iodized salt production to 4.1 million tons in 2003 and resulted in a major drop in the household coverage of iodized salt. Another survey done in the year 2002-03 reported a household coverage of 30% (22). According to the third round of National Family Health survey conducted in 2005-06, household coverage with adequately iodized salt was marginally increased to 51% (23).

The lifting of ban spurred the scientific community in conducting more research to generate scientifically valid information to address this challenge. A research conducted by International Council for Control of Iodine Deficiency Disorder (ICCIDD) in seven states during the period 2000-2006 reported that Iodine Deficiency Disorders remained endemic in these states (24). Studies conducted by National IDD Cell and other government agencies found that 263 out of 324 districts surveyed were endemic for IDD. None of the states or Union Territories was found to be free of IDD. Intense advocacy countering the claims made against the policy of Universal Salt Iodization viz. iodization leading to only marginal increase of price of salt up to 20 paisa per year, every individual being at risk of IDD as it is a disease of soil, and the fact that all the salt in India is produced, iodized, packaged and sold by national companies and most of the salt in India is produced by small and medium scale producers. Various stakeholders were engaged in informed debate.

Phase 4: Addressing "values", focus on sustainability (Since 2005) :

In the face of sustained advocacy and generation of evidence, Core Advisory Group on Public Health and Human Rights of National Human Rights Commission was asked in 2004 to critically examine the public health consequence of lifting of ban on mandatory salt iodization for human consumption. The Core Advisory Group suggested that the Universal Salt Iodization is a public health need which should be implemented throughout the country without nay relaxation in the ban on sale of non-iodized salt for human consumption. Consequent to this, the ban on sale of non-iodized salt was reinstated in 2005 (11).

There was also an attempt among various stakeholders to develop partnership for sustained advocacy and pushing the agenda of sustainable elimination of IDD. National Coalition for Sustained Iodine Intake (NCSII) was established with various stakeholders like government departments, office of the Salt Commissioner of India, academic institutions, research organizations, salt producers, bilateral and multilateral developmental organizations and civil society group. Efforts were also made to engage small and medium scale salt producers in ensuring the quality of iodized salt. Various innovative business models including introduction of iodized salt in Public Distribution System is also being implemented to increase coverage with iodized salt. This multipronged

approach with supply and demand side intervention led to a quantum jump in the household coverage with adequately iodized salt in India. Coverage Evaluation Survey (CES) 2009 reported that 71 % households are consuming adequately iodized salt with another 20% consuming salt with some iodine (25). The iodized salt production also increased to 6.2 million tons in the year 2010-11 (26).

However, a recent survey done in rural areas of 8 states with less coverage with adequately iodized salt shows, it remains low at 35.4 % to 64.1%. In these states, only 58.7% households were aware of iodised salt and only 35.4 % respondents knew that iodine deficiency causes "less mental development and diminished intelligence" (27). This led to more sustained advocacy, research in the reasons for low coverage in rural areas, and renewed focus on obstacles in achieving Universal Salt Iodization.

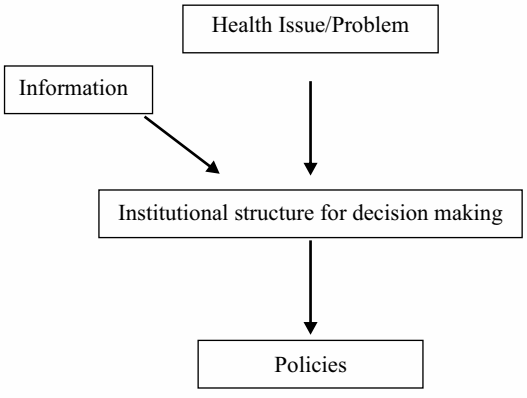

Figure 1: Environment in which policies are made

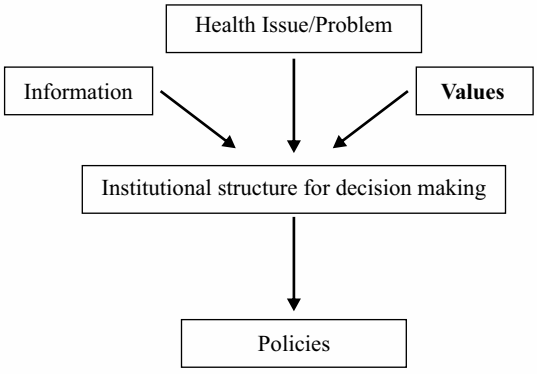

Figure 2: Environment in which policies should be made

Contextual frameworks of policy making environment :

Decision making process in formulation of policy and programmes is based primarily on the recognition of a problem as a "social or public health problem" and availability of an effective and efficient intervention, and decision making input. The success of IDD control

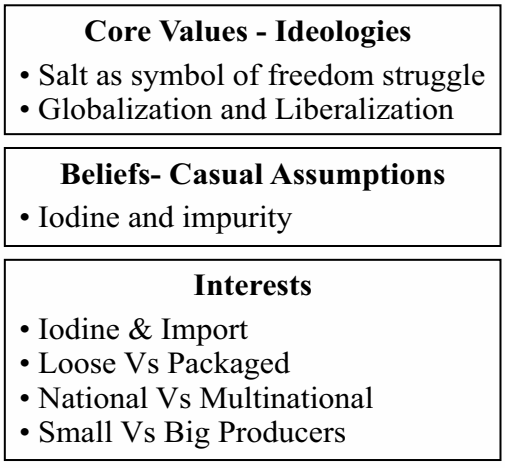

Figure 3: Values in the context of salt iodization

programme during 1983-2000 demonstrated the importance of decision making input. The recognition of IDD as a health problem and its solution existed since 1962. However, the programme got boost after got political support and decision making structure was institutionalized. Fig. 1 represents the environment in which policies were made. However, the reversal of ban on non-iodized salt in 2000 established the centrality of "values" in influencing the formulation of policies in a democratic set up (Fig. 2).

Values can be defined as "broad preferences concerning appropriate courses of action or outcomes". They operate at three different levels, namely core values or ideologies, beliefs and interests (Fig. 3). It was felt that the lack of focus on influencing the values of important stakeholders and the community at large was one of the major failures of NIDDCP. The core values relevant to the context were recognition of salt as a symbol of freedom struggle, and its positioning in the present day milieu as a fight between globalization and nationalization. The irrational belief of associating addition of iodine to salt as impurity further aggravated the negative value regarding iodized salt. The interest of salt producers and traders whose immediate benefits were associated with sale of non-iodized salt promoted the negative influence of core values and beliefs. However, once these values were addressed in right earnest, the programme faced least obstacle in implementation and has performed well. It was learnt that values should form an important input in policy formulation and programme implementation along with inputs like problem identification and scientific evidence for sustainability of policies.

Apart from addressing the values, development of enduring partnership among stakeholders is an important prerequisite for achieving sustainability. Regular Supply and demand side interventions are another prerequisite for achieving sustainability. Supply side interventions could be in the form of technical support, economic support or social support; demand side interventions could be in the form of altering community perception through sustained advocacy and legislations. Sustained political commitment and availability of regular and reliable scientific data is another requirement for achieving sustainability.

Discussion :

The case study of NIDDCP highlights the role of values, development of partnerships, and availability of reliable scientific data, sustained advocacy and political commitment in successful implementation of health programmes. The dynamic process involved in evolution and implementation of NIDDCP clearly delineated that health issues have social, economical and political ramifications. In the formulation of policy in a democratic environment, in addition to identification of the health

problem/issue, information in the form of evidence based data on effective and efficient intervention to eliminate the problem and formal and informal networks; there is a need to factor in "values". Neglect of values by the policy makers may lead to serious setback to the programme implementation as seen in case of NIDDCP.

This case study reinforced the need to carry out stakeholder analysis prior to development of any health policy and programme implementation. Stakeholder analysis is a process of systematically gathering and analyzing qualitative information to determine whose interests should be taken into account when developing and /or implementing a policy or a programme (28). Stakeholders include persons or organizations, which have a vested interest in the policy that is being promoted. Knowing who the key actors are, their knowledge, interests, positions, alliances and importance related to policy allows policy makers to interact more effectively with key stakeholders and increase support for a policy and programme.

The findings of the case study provided an understanding of a complex issue. The findings provided support to the conceptual framework put forward by us. Though the broad facts related to the study hypothesis were known before, this case study provided systematic evidence for the same. The findings of the study are relevant to the implementation of other health programmes in the country or even to other programmes related to social sector where people are important stakeholders. The findings can be generalized to other countries as well.

However, further research is warranted to understand the process of generation of "values" identified in the study. Systematic qualitative studies should be carried out to identify the determinants of these "values" and to develop appropriate interventions to modify them to aid the successful implementation of policy and programme.

Conclusion :

The major limiting factor in the implementation of NIDDCP was that the community perceptions about IDD and iodized salt and their values were not explicitly considered as part of implementation process. However, the programme performed much better when values of the stakeholders were addressed appropriately. In the formulation of a policy in a democratic set up, "Values" of the stakeholders play a vital role and should be incorporated as integral inputs into the process of policy making and programme implementation. However, development of partnerships, availability of reliable scientific data, sustained advocacy and political commitment is important for achieving sustainability of the programme.

Conflict of Interest : None

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