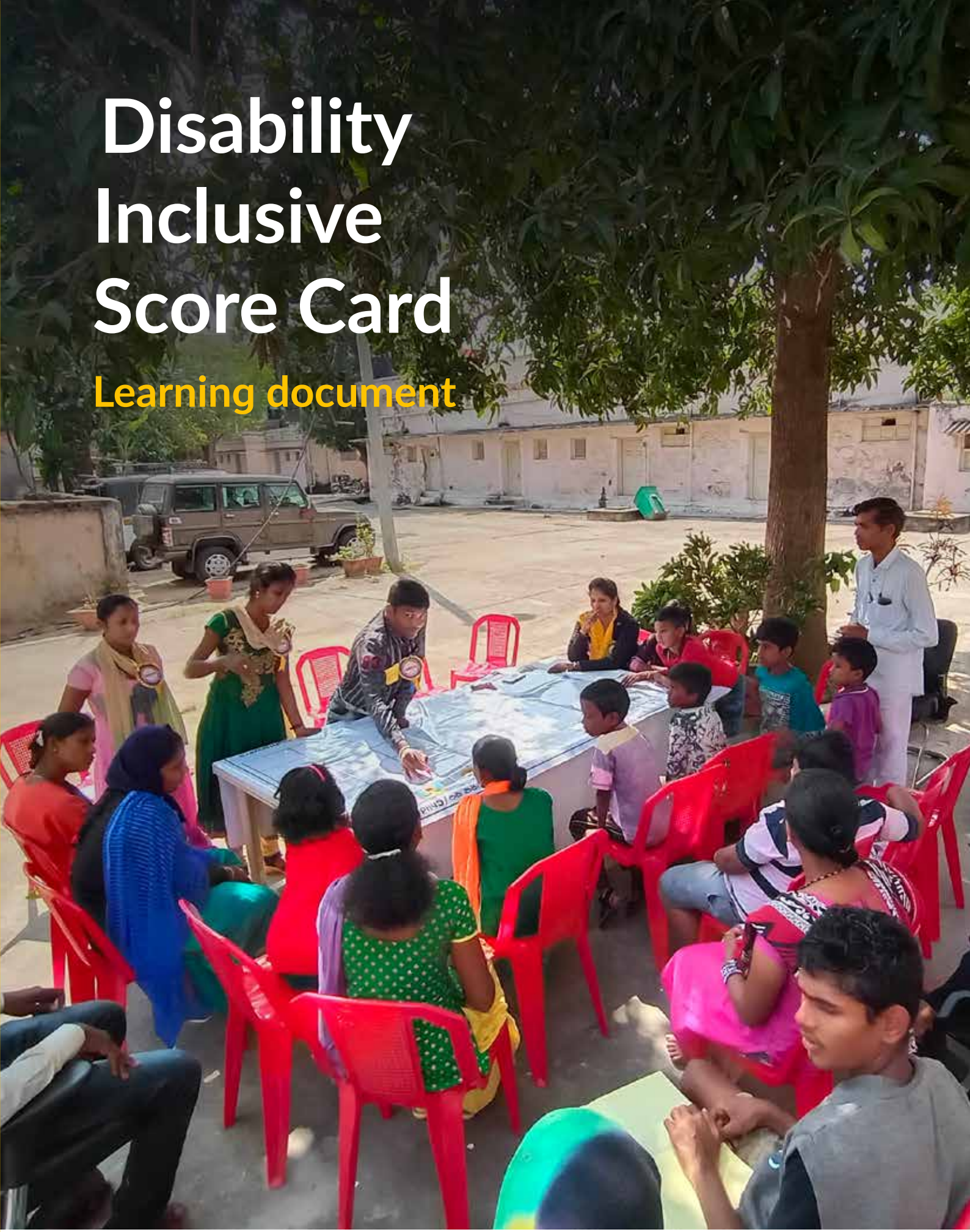
Disability Inclusive Score Card

Learning document



EUROPEAN DISABILITY FORUM

Newcastle University

Sightsavers

Contents

List of acronyms

CSC	Community Score Card
CVA	Citizens Voice and Action
DISC	Disability Inclusive Score Card
OPD	Organisation of People with Disabilities
EU	European Union
RPWD Act	Rights of Persons with Disabilities Act, 2016
RTE Act	Right of Children to Free and Compulsory Education Act
SDGs	Sustainable Development Goals
TLM	Teaching and learning materials
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Acknowledgements

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Executive summary

Introduction

The Disability Inclusive Score Card (DISC) project was developed by Sightsavers India is an innovative approach to social accountability for people with disabilities and is grounded in human rights and the Sustainable Development Goals (SDGs). To aid reflection on the tool, and to help others adopt and potentially adapt the method, this document reports on the pilot phase of the DISC project in the context of educational provision for children with disabilities in five locations across India. This summary and the full report it is taken from, aim to:

1. Highlight and discuss distinctive aspects of the DISC methodology.
2. Present key outcomes from the five pilot locations that demonstrate the effectiveness of the approach.
3. Discuss key learnings on DISC from the pilot phase, highlight advances in practice and share recommendations for wider adoption.

The DISC methodology

DISC aims to assess a service and generate an action plan for improvements. Participants begin by selecting issues that need to be assessed through a set of key indicators related to the service (in this case, education). They then go through a series of steps that include voting on a pre-determined scale with shared reasoning and discussions in small groups. This process results in an action plan for improvement in which the users of services, as well as the providers, have a role to play.

The DISC approach is developed as a combination of the Citizens Voice and Action (CVA) and Community Score Card (CSC) concepts. DISC is similar to CVA in the level of service covered and the role of community members but gives service providers a larger role. DISC also follows the CSC approach in determining the issues addressed using the tool. The depth of the input tracking and nature of the action plan is also similar as individuals still assess each indicator on a scale of 1-5. But these individual scores are not consolidated or averaged. Instead each individual votes for the rating they deem appropriate and it's then these votes that are presented as the result.

DISC acknowledges gender by:

- Having dedicated focus group discussions among girls and women with disabilities.
- In selecting women representatives to present the scorecard at the interface meeting.
- Ensuring specific action and messaging around gender dimensions in the scorecard's follow-up advocacy activities.

DISC acknowledges disability by:

- Selecting facilitators from members of organisations of people with disabilities.
- Choosing venues that are accessible to people with different types of disabilities.
- Ensuring that all participants are comfortably and conveniently seated in chairs around a table throughout the exercise.
- Implementing an agenda that gives adequate time to allow all participants a fair chance to engage and contribute.
- Providing assistance in the form of volunteers to help participants to actively take part in the proceedings.
- Allowing for support participants such as caregivers or parents to speak and participate on the participants' behalf, particularly for children and adults with intellectual impairments.

DISC spreads knowledge of the SDGs and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and is informed by the SDGs emphasis on vulnerable and marginalised groups. But the specific entitlements used as a framework for the exercise are generated from national and local legal entitlements such as the Right of Children to Free and Compulsory Education Act (RTE Act) and the Rights of Persons with Disabilities Act, 2016 (RPWD Act).

Participants across all the five pilot locations were similar and comprised of the members of Organisations of People with Disabilities (OPDs), people and children with various types and levels of disabilities and junior level officials from relevant government departments. Gender parity was also maintained while selecting the participants.

A key difference among pilot locations was the level of participation from public officials. Though similar efforts were made in all five pilots to ensure the participation of officials, the state of Chhattisgarh saw the highest attendance of officials while in Rajasthan, fewer officials participated in the interface meeting. These differences impacted the action plans to some extent.

Key outcomes

Follow-up interviews and feedback identified several positive outcomes from the pilots:

- Increased knowledge and awareness among the stakeholders about the entitlements and issues of people with disabilities.
- Creation of a path for constructive engagement with authorities. OPD personnel are being recognised as an important resource for the education department which is a good starting point for longer-term cooperation.
- Attitudinal changes and realisations among officials of government departments as well as parents of children with disabilities. Officials who had not previously thought of facilities for people with disabilities started assessing the accessibility of buildings. Officials that considered people with disabilities as an unproductive burden to society started seeing them as useful resources. Parents also realised that it was possible for their children with disabilities to lead fulfilling lives.
- Empowerment of members of OPDs and people with disabilities through equipping them with necessary information.
- Realisation among OPDs that through collective efforts it is possible to change the state of services and facilities for people with disabilities.
- Though the COVID-19 pandemic did affect the follow-up activities on the action plan, there have been some promising developments across states. For example, accessibility audits have been conducted for several schools by OPD members, letters have been sent to district level officials with requests following the action plans and sensitisation and awareness-building efforts among community members and officials is ongoing.

Learning and insights

The DISC process successfully brought about attitudinal change among all stakeholders. They initially held a 'nothing will change' attitude but DISC allowed disabled people to realise the possibilities collective effort has to offer.

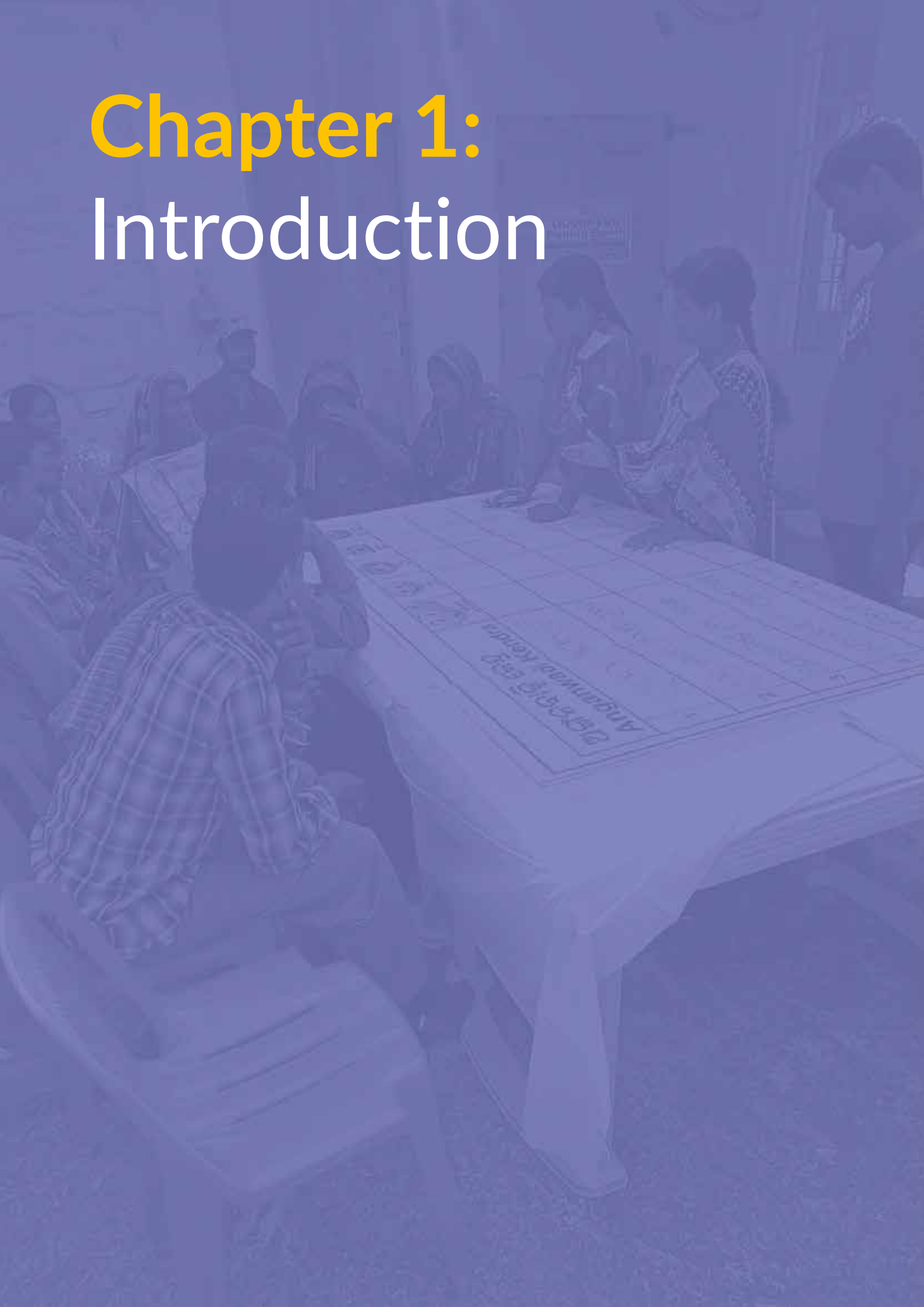
- Facilitation is everything – a good facilitation team with a strong understanding of the local language is extremely important for the success of DISC. In particular, there is a definite possibility of influence by facilitators in the voting phase which facilitators must be wary of.
- Rapport building is key – for effective participation of officials and community members, rapport building is crucial. The implementation team must significantly invest in this exercise.
- Barriers to participation – bringing children with disabilities from different geographical locations to a common venue is challenging. Participation of people with severe disabilities is also challenging and only those with mild disabilities (mostly physical) engaged in some of the DISC exercises.
- Input tracking is a key element of the DISC process and needs to be done more efficiently and thoroughly in future exercises.
- In practice, action plans were generated without sufficiently broad participation. In most locations, there was no participation from children, parents or service providers and with only members of OPD playing an active role. This is something that future exercises could address by involving representatives of service providers as well as parents in the preparation of action plans.

Conclusions

The DISC process was found to be easy to follow and perceived as beneficial by all stakeholders. As an approach, it is gender-inclusive, disability-inclusive and constructive, generating both greater awareness and future cooperative action. It is a powerful knowledge sharing tool, especially when further refined and developed beyond the pilot phase, and has potential for use across many other sectors.

For those who are interested in knowing more about DISC can refer to the manual and the learning document produced by Sightsavers. To develop and collaborate around DISC, please contact Sightsavers India.

Chapter 1:
Introduction



Introduction

The 2030 Agenda for Sustainable Development and commitment to the Sustainable Development Goals (SDGs) in 2015 recognises the need to reach everyone everywhere, especially those who have been too often neglected, such as people with disabilities. The Rights of Persons with Disability (RPWD) Act of 2016 recognises 21 categories of disabilities and lays complete emphasis on one's rights which include: the right to equality and opportunity, the right to inherit and own property, the right to home and family and reproductive rights.

A consistent way to ensure that people with disabilities are reached and disability inclusion remains a priority, is by creating pathways for organisations of people with disabilities (OPDs) to help monitor whether governments are delivering on their promises and whether what has been included in the RPWD Act is being translated into action, particularly at the local level.

Building Partnerships for the SDGs – Empowering Disabled People's Organisations, an EU-supported project that is implemented by Sightsavers India, aims to facilitate these opportunities using a Disability Inclusive Score Card (DISC) which evolved as a combination of the Community Score Card (CSC) and the Citizens Voice and Action (CVA) approaches.

Project objectives

The project was conceived with the following objectives:

- To bring together service users and providers to jointly analyse the underlying service delivery problems and to find collaborative ways to address these issues.
- To empower people with disabilities to know and claim their rights and to increase the ability and accountability of individuals and institutions that are responsible for respecting, protecting and fulfilling those rights.
- To facilitate opportunities for people with disabilities to gather and present evidence that can help drive effective decision-making.
- To provide an inclusive and participatory approach to ensuring disability inclusion in the implementation of the SDGs.

Coverage

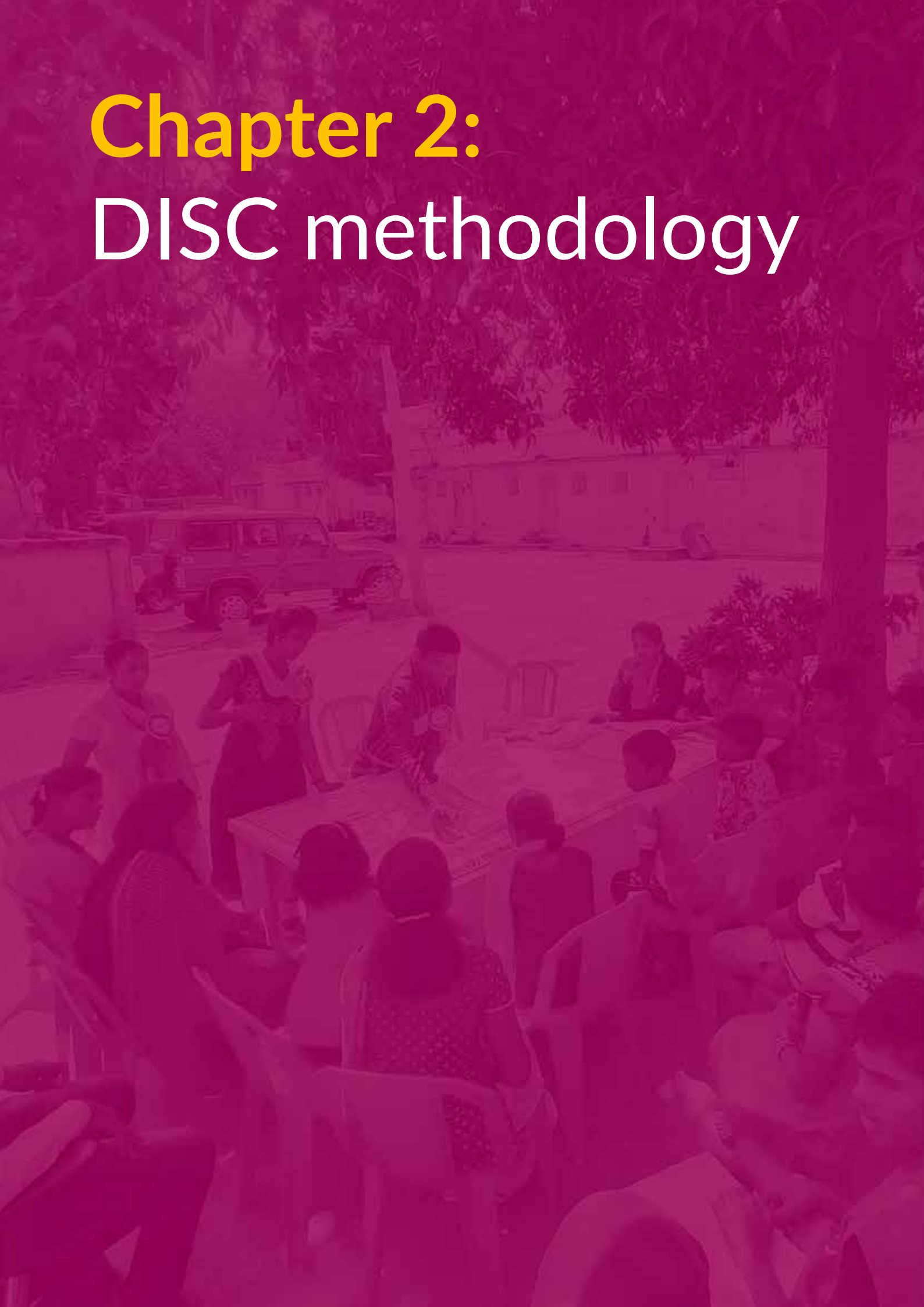
DISC is a tool that can be used to assess the quality of any service made available to people with disabilities. In partnership with Samarthyam, Sightsavers India has pilot-tested DISC at three levels: Anganwadi, primary school and middle school services. The pilot took places in five places across India: Sihora in the state of Madhya Pradesh, Hazaribagh in Jharkhand state, Raipur in Chhattisgarh state, Ganjam in the state of Odisha and Chittorgarh in Rajasthan state.

The first exercise that was held in Jabalpur, Madhya Pradesh was a teaching of the trainers. This was attended by both regional and Delhi-based Sightsavers staff. Selected members of OPDs from the five states of Madhya Pradesh, Chhattisgarh, Jharkhand, Odisha and Rajasthan participated alongside resource staff from Sightsavers India and Samarthyam. Also, in attendance was Mr Jacob Devabhaktula, national coordinator at Disability Initiatives (World Vision), who is experienced in conducting the CVA in various contexts in different states of India at World Vision. Dr Sita Sekhar, an independent governance and social accountability expert was part of the exercise as a documenter and technical advisor. The methodology evolved during this exercise was subsequently tested in the remaining four states.

Based on the pilot exercises, this learning document has been prepared to encapsulate the experience and to understand what worked well, what did not, what should be done differently while replicating the exercise or scaling it up and what learnings or recommendations emerge from this exercise for others who would like to conduct similar exercises.

[1] Care about Rights, Scottish Human Rights Commission http://careaboutrights.scottishhumanrights.com/whatisahumanrightsbasedapproach.html

Chapter 2:
DISC methodology



Methodology

The Disability Inclusive Score Card (DISC) is a tool developed as a combination of the Community Score Card (CSC) and the Citizens Voice and Action (CVA) approaches. The DISC is explicitly rights-based and uses the scorecard to make people with disabilities aware of, and claim, their entitlements.

The Community Score Card is a community-based monitoring tool with a strong focus on empowerment and accountability. It brings together the demand side ('service user') and the supply side ('service provider') of a particular service or programme to jointly analyse the issues underlying service delivery problems and find a common and shared way of addressing them.

CVA is a local level advocacy and social accountability approach that facilitates dialogue between communities and government in order to improve services (like healthcare and education) that impact the daily lives of children and their families.

For ease of understanding, the similarities and differences between CSC, CVA and DISC have been outlined in Table 1.

Table 1: CSC vs CVA vs DISC

	Characteristic or element	Community Score Card (CSC)	Citizens Voice and Action (CVA)	Disability Inclusive Score Card (DISC)
1	Level of service covered	At the facility level. For example, a school, Anganwadi or health centre at a village location. Members of the community who participate would be service users of that facility.	At local but not at the facility level. A combination of facilities in several villages at district or state level could be covered. The focus is on policy.	Similar to CVA, a combination of facilities in several villages at district or state level is covered. However, the focus is on different levels of services and not only policy.
2	Input tracking	Thorough and elaborate. Input tracking follows a process of collecting information on the facilities available and includes three processes: physical verification (observation), verification of records and interviews of stakeholders.	Minimal tracking including a table that lists out the provisions of law for the services covered.	Same as CSC.

	Characteristic or element	Community Score Card (CSC)	Citizens Voice and Action (CVA)	Disability Inclusive Score Card (DISC)
3	Inclusion of feedback from service providers	Service providers develop indicators of good service. They score these and give reasons and recommendations. They also participate in an interface meeting to decide a shared score with the community and participants in the development of the action plan. Service providers who participate in the exercise are from unit level as well as from the block, district or state level.	Service providers are not included in any stage except the interface meeting. Members are mainly from the higher levels or from the local level of the concerned department.	Discussions are held with service providers to identify issues and give suggestions. They are also included in the interface meeting.
4	Seeks feedback from relevant community	The community develops indicators of good service. They score five to eight that are critical to their priorities through a consensus process which they run themselves. They also give reasons for the score and recommendations. In the interface meeting, they consult with service providers and arrive at a consensus score. They also participate in action planning.	The community scores four or five set indicators (which are taken from provisions of the law) by an indirect method of individual voting which is then used to calculate scores for each provision. The community doesn't have a role in the action plan process.	The community has the same role as in CVA. However, the logistics of voting have been designed to be practical to people with disabilities. Instead of four or five set indicators or provisions, the community is asked to prioritise five to eight which they think are critical and vote on those. Members of OPDs represent the community in the action plan process.

	Characteristic or element	Community Score Card (CSC)	Citizens Voice and Action (CVA)	Disability Inclusive Score Card (DISC)
5	Includes interface meeting	The interface meeting has all stakeholders present and participating. Service providers (including senior level officials and political leaders) and members of the community that did the scoring in groups interact and arrive at consensus scores for each indicator. Those indicators that are rated low are then worked on to jointly develop the action plan.	The interface meeting has all stakeholders present. Service providers get an opportunity to provide explanations for the state of services and answer queries from the community. They are also able to give assurances on what they intend to do. However, they are not involved in the making of the action plan.	Very much like CVA but with one small addition. Service providers' promises or statements are included in the action plan and where possible, their representatives are involved in the action planning process.
6	Participants in preparation of action plan	All stakeholders: the community, service providers and government officials.	The local organisation that carries out the CVA or select members of the community.	Members of OPDs act as representatives of the community, people with disabilities and service providers (directly or indirectly).

	Characteristic or element	Community Score Card (CSC)	Citizens Voice and Action (CVA)	Disability Inclusive Score Card (DISC)
7	Nature of action plan	The action plan is developed to include actions by the community and service providers at different levels including at local and policy level. Short-term, midterm and long-term actions are also specified with resources required defined timelines.	The action plan is largely targeted at the policy level.	Same as CSC but without direct participation from the community and service providers.
8	Issues addressed	Small to large issues are addressed to find solutions at different levels.	Largely related to making changes in law or their implementation.	Same as CSC.

Gender consideration

The tool provides an opportunity to take the specific rights and needs of girls and women with disabilities into account. DISC requires balanced gender consideration while implementing several steps of the tool. These include:

- Having dedicated focus group discussions among girls and women with disabilities.
- Selecting women representatives of the OPD to present the scorecard at the interface meeting.
- Ensuring that specific actions and messaging around gender dimensions in the scorecard are followed up in the joint action plan and advocacy activities.

Reasonable accommodation

Selection and sensitisation of facilitators – Participants in the DISC process are either people with disabilities or their family members. DISC emphasises the need to carefully choose the facilitation team and train them properly to be sensitive to participants in their planning and conduct of all the steps of DISC. In most cases, the team of facilitators is picked from the OPD members. This not only helps to empower them but also makes it easier for participants as the facilitators are aware of the issues related to people with disabilities.

Venue and other logistics – Logistics are planned to ensure accessibility for people with different types of disabilities. The DISC process is implemented in small groups, which makes access to the necessary materials easier for all participants. Care is taken to ensure that the venue has accessible toilets and is located as close to the community as possible to minimise long journeys. The venue is also reviewed to confirm that there is enough room to move freely and the floor is suitable for wheelchairs to easily move around. Ideally, people using wheelchairs or walking aids should be able to access all areas of the venue, not just the room where the event is happening.

Seating and other arrangements – All participants are comfortably and conveniently seated in chairs around a table throughout the exercise. Comfortable chairs with good back support are provided and cushions are made available if chairs do not have back support. Seating is set up to ensure that people who lip-read can see everyone else's face. Other items (such as tea urns, leaflet tables and flipchart stands) are set at a height that everyone can access or be easily moveable.

Time management – Extra time is allocated to meet the needs of participants to discuss issues, process their thoughts and engage effectively with the group. The agenda allows for adequate time to provide all participants a fair chance to engage and contribute.

Assistance to ensure participation – The DISC facilitation team comprises of volunteers who are trained to help the participants by:

- Explaining and interpreting the participant's role in every exercise of the DISC process when needed.
- Translating the instructions where necessary.
- Providing sign language interpretation where necessary.
- Assisting participants with physical and visual impairments to get from one place to another for group meetings and voting exercises.
- Assisting participants in any other manner needed to actively take part in the proceedings.

Support persons – Some participants, particularly children and adults with intellectual impairments, may find it difficult to express themselves in this exercise. Therefore, the design of DISC allows for support persons such as caregivers or parents to speak and engage on behalf of the participants. This is to ensure that the concerns of all participants are included in the overall process.

Knowledge sharing

The DISC exercise generates and shares learnings across all stakeholders and acts as a knowledge sharing platform. During the pilot testing, service providers, service users and members of the OPD were told about their entitlements related to education and Anganwadi services.

Participants were told about the Sustainable Development Goals and what they mean to people with disabilities.

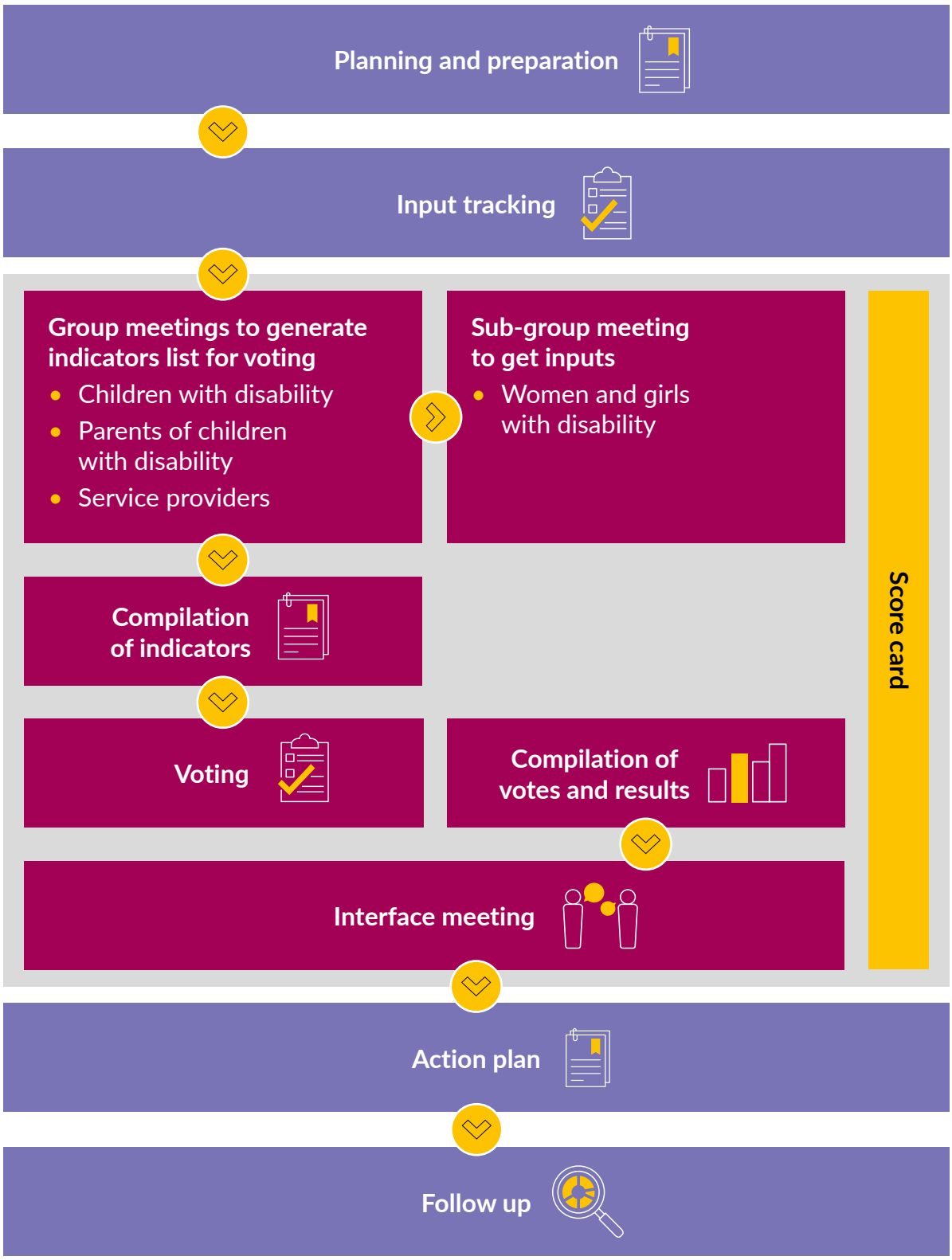
Specific but detailed entitlements to children and people with disabilities under the RPWD Act and RTE Act were listed and used as a framework to share with the participants during the preparations and planning stage of DISC.

DISC process

The DISC process comprises of the following steps:

1. Planning and preparation
    - Stakeholder mapping
    - Orientation of community and service providers on the RTE and RPWD Acts
    - Orientation of community and service providers on DISC and their role
2. Input tracking
    - Physical observation
    - Interviews with key informants
    - Verification of records
3. Group meetings to discuss the challenges and to develop indicators with:
    - Children with disabilities
    - Parents of children with disabilities
    - Service providers
    - Women and girls
4. Voting on indicators agreed upon during group meetings
    - Compilation of total votes and results
5. Interface meeting with all stakeholders
    - Presentation of results
    - Responses by service providers
6. Preparation of action plan on low scoring indicators
7. Follow up on implementation of action plan

Figure 1: DISC process diagram



Roles and responsibilities

There are several stakeholders involved in planning and implementation of DISC. The facilitators who are responsible for conducting the DISC meetings are critical to the exercise and must be carefully chosen. Ideally, these are OPD members from the local area.

Facilitation team: The facilitation team includes a coordinator who oversees the DISC exercise, a moderator who facilitates the various steps and a scribe who documents the proceedings of the exercise. A team of volunteers, who are also mostly members of the OPD, assist the participants with various steps of the DISC process. A team of two or three people help in the compilation of indicators and votes.

Participants: Participants are broadly from two groups – service users and service providers.

Service users: Include persons with disabilities using the Anganwadi services, children with disabilities attending primary and middle schools, parents of these children and members of OPDs.

Service providers: Include unit level officials like teachers and Anganwadi workers and block and district level officials from the relevant departments like block resource person and block development officer. Junior level officials were present during all meetings of DISC and participated in all the steps while the senior officials mostly only participated in the interface meetings.

Summary comparison

As mentioned earlier, the pilot exercise was held in five states. Though the format of the exercise was similar in all states, there were subtle changes to the process to suit local conditions. The level of involvement of different stakeholders and the follow-up impact of the action plan has been different in each state. A comparative summary of the pilot exercises in the five states, based on the following parameters, is given below:

- Categories of participants
- Accessibility of the venue
- Time taken for the DISC exercise
- Co-operation from officials – attendance and responsiveness
- Action plan
- Follow up on action plan

Categories of participants: Participants across all the five states were similar and comprising of members of OPDs and people and children with various disabilities such as blindness and orthopaedic disabilities. Service providers were represented by junior officers of government education departments, resource teachers, special educators, head of schools and Anganwadi workers. Gender parity was maintained while selecting the participants.

Accessibility of the venue: Across the states, not all venues were accessible to children and people with disabilities and finding an accessible venue was a challenge.

Time taken for DISC exercise: The pilot exercises were held over three days and a similar agenda and format were used across all five states. The first day included the orientation to the team and the DISC exercise followed over the next two days.

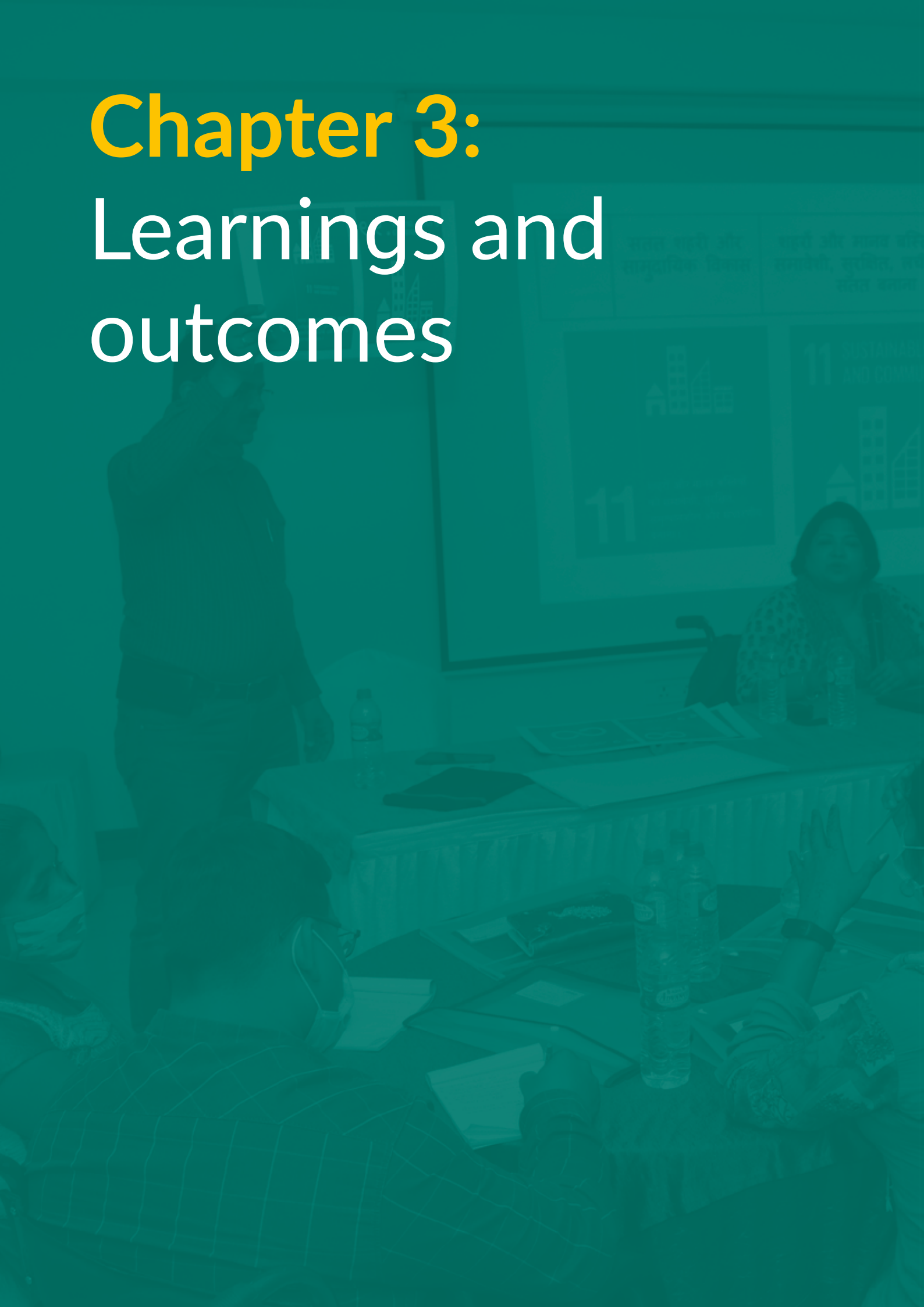
Co-operation from officials: Invitations were sent to service providers a month in advance. Regular reminders were given to both service providers and users to ensure their presence and meaningful participation. A good number of officials participated in the DISC exercise across states. Junior level officials were present for scoring while senior level officials attended the interface meeting. The state of Chhattisgarh saw the highest turnout of officials with 23 attending. In Madhya Pradesh, Odisha and Jharkhand around nine officials participated. In Rajasthan, six officials participated and this included fewer senior officials participated which impacted the action plan to some extent.

The action plan: Across states, the action plan prepared by the participants varied. Some had very specific and actionable objectives across the short, medium and long-term while others were more generic. The following table gives details on the nature of the prepared action plans.

Table 2: Nature of DISC action plans across states

Sihora Madhya Pradesh	**Hazaribagh** Jharkhand	**Raipur** Chhattisgarh	**Ganjam** Odisha	**Chittorgarh** Rajasthan
The action plan was mostly restricted to audits of facilities such as Anganwadi centres. This was to understand if they are accessible to people with disabilities.	The action plan was mostly restricted to writing letters to concerned officials in the relevant departments as well as in-person requests and discussions.	The action plan included a combination of different interventions. This involved awareness building, accessibility audits and coordination between two government departments to make study materials available.	The action plan included a combination of short, medium and long-term actions. These related to building new infrastructures, adding modifications to existing ones, training staff on sensitisation, writing letters to concerned officials and one-on-one meetings and discussions.	Specific items have not been detailed in the action plan.

Chapter 3:
Learnings and outcomes



A few months after conducting the DISC exercise, feedback was collected from a sample of stakeholders who were involved in pilot exercises in the five states. The time gap was given to allow any follow-up actions to take place before contact. Telephone feedback was collected by Dr Sita Sekhar, a consultant hired by Sightsavers to assess the impact of the pilot exercise from the following stakeholder groups:

- Children with disabilities
- Parents of children with disabilities
- Officials
- OPD members
- Sightsavers staff members

The feedback was used to identify what went well and what did not. It also looked at the perceived strengths and shortcomings of DISC and the specific areas where the process might be improved. Despite the advent of COVID-19 soon after DISC was initiated, there were many interesting outcomes that are documented here.

Key outcomes

Increased knowledge and awareness among stakeholders

- Increased the knowledge and awareness among the stakeholders about the entitlements and issues of people with disabilities.
- All participants, including service providers and education department officials, benefited from the information about RTE and RPWD Acts that was shared in the DISC exercise.
- DISC also helped participants gain knowledge about the accessibility audit which was very useful for OPD members.
- The process helped educate parents about what their children are entitled to at their education facilities. Some parents did not know about the School Development and Management Committee so learnt about the role it can play in making services available to children with disabilities. They also understood their responsibilities, the value of educating their children and took steps to ensure that they received appropriate services. Parents of children without disabilities were also invited to the exercise which sensitised them to the issues faced by children with disabilities.
- After the DISC exercise, OPD members have become more aware of their entitlements and are constantly thinking about what can be done to make life easier for people with disabilities which includes making facilities more accessible.

Creation of a path for constructive engagement

- Members of OPDs have realised that collaborative efforts work better in resolving issues rather than confrontational means.
- Higher officials of government departments have become more accessible to OPD members. The service providers' response is better because of the fact-based arguments and in-depth knowledge put forth in the DISC process.
- The interaction of OPD members with officials after the DISC exercise has been meaningful. In one state, the education department officials held a meeting and invited the members of OPDs to discuss how to make their facilities more accessible to children with disabilities.
- DISC provided a forum for teachers to be honest in admitting the quality of services available for children with disabilities and to cast their votes without fear or hesitation.
- Through DISC, a network of people with a common purpose was established which is useful to address issues.
- Despite the state of Chhattisgarh not having a programme on inclusive education, DISC helped by raising the concerns of the children with disabilities and bringing them to the attention of the concerned stakeholders.

Empowerment of members of OPDs and people with disabilities

- Post-DISC, members of OPDs feel more empowered and confident to approach the service providers.
- The rapport with service providers has improved since the DISC exercise and OPD members feel more confident to interact with them about any issues they face.
- DISC has helped the OPD members learn how to get children with disabilities to open up and share their issues and concerns.
- Members of OPDs are making personal efforts in building awareness in their areas about the entitlements of people with disabilities since DISC.
- For many years, member of OPDs have been asking for better services for people with disabilities. But with DISC, the same work is being done with more knowledge and as a rights-based approach which is game-changing according to many OPD members.

Realisations and attitudinal changes

Even though the focus of DISC in the pilot exercise was largely on access-related issues, it was heartening to see that the process brought about significant attitudinal changes among stakeholders almost instantly. This was totally unexpected. Parents of children with disabilities started out with the fear that service providers would not interact with them but were pleasantly surprised and motivated when they saw that they did. 'Nothing will change' was the attitude of stakeholders prior to DISC and this belief has diminished after the DISC exercise. Now all stakeholders feel that with collective efforts it is possible to make things change for people with disabilities.

- There has been a change in the attitude of OPD members; from asking for help, they now ask/demand for their entitlements.
- Many service providers felt that DISC was a good tool for assessment. The direct interaction with children with disabilities was an eye-opener for them. The process made them realise that 'it is not sympathy that people with disabilities need; it is motivation that is required'.
- The psychological behaviour of some officials changed because of participating in DISC exercise. They decided to go beyond the call of duty and realised that it is not only being sensitive but being socially responsible that is required.
- Many officials are exceeding targets in providing aid and equipment to schools post-DISC. Some are also trying to integrate the approach beyond elementary school into higher education (high school and college).
- Parents are being taught how to make children with intellectual disabilities self-reliant and to not stereotype children with disabilities. Instead, they are focussing on programmes for developing the children's skills so they can live an independent life.
- Since the DISC exercise, it was realised that inclusive education is not just the responsibility of the education department and other departments also have a role to play. The Education, Health and Social Welfare departments should work together to meet the requirements of the children with disabilities and with a better use of available funds. It is not just teachers and officials from the inclusive education department that must be sensitised about the need for inclusive education but also all education department and Department of Public Instructions officials.
- DISC helped in building an understanding that it is not just important to make the school accessible to children with disabilities but they also require disability-inclusive and accessible teaching methods, aid and teaching learning materials.
- Some teachers felt that the exercise was being conducted to bad-mouth or blame them as being insensitive and inefficient.

Follow-up on the action plan

The COVID-19 pandemic did have an impact on the follow-up efforts by OPD members on the implementation of action plans. There has still been good progress made in certain states due to the efforts by dedicated OPD members as well as some proactive officials and staff members from government departments. The following table lists some of the follow-up efforts made on the action plans across states:

Follow-up efforts in Sihora, Madhya Pradesh:

- Findings were shared with OPD members which led to advocacy efforts.
- As the Jabalpur exercise was an experiment where the DISC process was evolved, it was the team's own initiative to implement DISC in Hoshangabad.

Follow-up efforts in Hazaribagh, Jharkhand:

- As per the action plan, letters were sent to the inclusive education department and district administration.
- The DISC process increased the visibility of OPD members in the government and OPD members were then included in the COVID-19 action programme.
- Engagement with district officials has increased post-DISC.
- As a spin-off from DISC, an accessibility audit of election venues was conducted which included, not just physical accessibility, but also ballot papers in braille for the visually impaired.

Follow-up efforts in Raipur, Chhattisgarh:

- Accessibility audit was conducted in four schools.
- Anganwadi workers were sensitised and children with disabilities were enrolled to Anganwadi centres.
- Parents were sensitised to return children with disabilities to mainstream schools rather than send them to special education schools.
- There was a discussion about facilities for children with disabilities in a SDMC meeting.
- OPD members helped some families to get disability certificates.
- Bicycles were arranged for some girls.
- Assistive devices were provided for children with visual impairment.
- The attitude of parents towards their own children (children with disabilities) has changed for good. What was seen as a burden has changed to the belief that they can be independent and self-resilient with proper training and motivation.
- Accessible learning books have been made available in the department's digital library that can be downloaded on smartphones to aid the learning process.
- The children have started demanding accessible environments not only in schools but in all public offices.
- In a school where toilets were being constructed, it was ensured that the toilets were made wheelchair accessible. It was also suggested that they were colour contrasted for people with low vision but this was not implemented.
- A suggestion was also made to make the stage accessible to children with disabilities.
- OPDs are being considered as an essential part of human resource in the education department which is a good beginning of cooperation.

Follow-up efforts in Ganjam, Odisha:

- As a follow-up in Odisha, an OPD member audited the accessibility of a school all by himself. He then shared the information with Anganwadi workers on their roles and responsibilities post-DISC.
- There has been a dialogue between the district inclusive education coordinator and district collector to implement the action plan.
- As per the action plan, letters on behalf of OPDs were sent to concerned officials of the departments.
- Post-DISC, Sightsavers India has budgeted for a solution document for an inclusive village after studying issues in five to seven villages. These issues include physical accessibility, the Mahatma Gandhi Employment Guarantee Act 2005 and lake ponds. But due to the pandemic, this work has not yet begun.
- There was no training resource available for teachers to learn how to interact and teach children with disabilities. Post-DISC, the government of Odisha's Department of Education has developed a module called Udhyam. This module has been approved by the State Council of Educational Research and Training for classes 1 to 5 and has been printed and circulated to all schools by Sightsavers. A similar module is being developed for classes 6 to 8.
- Post-DISC, Ganjam has been included in Sightsavers' inclusive education programme alongside Koraput.
- Master training has been given by the education department on the Udhyam module.
- There has been a change in the attitude of teachers. This not only benefits children with disabilities but also changes the behaviour of all children towards children with disabilities.
- People with disabilities have been included in some mothers' committees at Anganwadi centres.
- A programme on sensitising people about the effects of verbal abuse towards people and children with disabilities was conducted.
- Schools where children with visual impairments and physical disabilities attended were audited.
- To build awareness, discussions were held with teachers and headteachers about the rights and entitlements of children with disabilities.
- Teachers and Anganwadi workers were sensitised and now demand better services and facilities for children with disabilities.

Follow-up efforts in Chittorgarh, Rajasthan:

- As per the action plan, letters were given to the district collector.
- The team has planned to implement DISC in other panchayats.
- The team wants to develop a model panchayat using DISC for all services and not just education.
- Post-DISC, visually impaired children have been admitted into mainstream schools.
- Age-appropriate crutches have been given to a few children with disabilities.

Learning and insights

DISC is a very useful tool

The consultative nature of the DISC exercise has empowered stakeholders and provided them with the necessary information and incentive to make a difference for people with disabilities.

Most stakeholders who participated in the DISC exercise have expressed the need for, and possibilities of, using the tool to assess other services like higher education, health, rural upliftment and backward community upliftment.

Both service user and provider stakeholders have acknowledged the value that DISC can bring in the betterment of the lives of people with disabilities. They have expressed the need to repeat the DISC exercise to maintain motivation as well educate new staff due to high turnovers in government departments.

Some officials and OPD members have also expressed the view that by repeatedly conducting DISC, corruption can be reduced in the long run.

During the DISC exercise, the entitlement information was provided in the local language (Odia) and has been proactively used by OPD members to build awareness at the local level.

Rapport building is key

DISC is a consultative process whose success depends on the quality of participation of all concerned stakeholders. This can only be attained when the implementing OPD has a good rapport with the community members and officials. This is a time-intensive process that involves strategic thinking and collaborative efforts from the OPD and needs to be initiated in advance of planning and implementing DISC. Rapport building is a continuous process that cannot and should not be thought of as a one-time effort by the implementing OPD.

Among the five states where the pilot exercise was held, the state of Chhattisgarh had the maximum attendance and involvement of officials at different levels. A major contributing factor was the effort put in by the OPDs and local staff of Sightsavers in building rapport with the officials of the government departments.

Barriers to participation

Though similar steps were taken to obtain consent from officials to participate in the DISC exercise, the level of involvement was not the same across all states. In some states, the attendance and responsiveness of officials was very encouraging while others did not see a similar reception. In Rajasthan, the low level of involvement from officials impacted the action plan preparation and the follow-up exercise. There were no senior officials present from either the Integrated Child Development Services or Ministry of Women and Child Development at most locations. This led to there being nobody to respond to issues related to Anganwadi services.

Bringing children with disabilities from different villages to a common venue was difficult. Children with mild disabilities (mostly physical) could participate in the DISC exercise in some states but those with severe disabilities could not. This may result in those with severe disabilities missing out and not receiving the benefits from DISC.

The weather was unpredictable in some states. This meant that the exercise could not start on time and some of the participants and officials could not make it to the venue.

The distance to the venue was a problem for officials and people with disabilities. Finding affordable and accessible venues was a big challenge.

Facilitation is key to success

One inherent disadvantage of any tool such as DISC is that the voting can be influenced by the facilitators. Utmost care must be taken in the selection of facilitators and briefing them on their roles and responsibilities in the DISC exercise. They must also remain unbiased and aware of the larger impact that they will have on the overall outcome of the exercise.

Scope for process improvement

Input tracking is important to understand the situation on the ground and to be able to challenge service providers if any false claims are made. The findings from this input tracking should be shared with all participants as part of the DISC process. However, this important step was not implemented in most states.

Combining Anganwadi and education services led to providers not being interested when discussions on the other service were going on. Interface meetings should have been conducted in separate groups for each service.

The time given for OPD members to understand the DISC process and the RTE and RPWD Acts was insufficient. Some of the OPD members found it difficult to comprehend all the information that was shared with them within the time frame.

The training and orientation of DISC to OPD members and the actual exercise should not have been held on consecutive days. DISC should have been implemented after a week or two after orientation. This would have helped participants to understand it better.

To some extent, members of OPDs, parents and service providers were influenced by the position or opinions held by Sightsavers and trainers. This resulted in a divergence between scoring and the action plan.

All stakeholders should have participated in the action plan preparation. In most states, there was no participation from the children, parents or service providers.

Non-Governmental Organisations and Panchayat members should have been involved in the process.

Recommendations

Preparation and planning are very important. Equal care must be taken when organising an accessible and affordable venue. It is preferable to look for a free venue like a Gram Panchayat community hall or school, rather than a paid one but they must be accessible to people with disabilities. The dates for conducting the exercise should be carefully considered and decided in consultation with service providers to ensure their participation. Detailed entitlement matrices and all relevant information necessary for orientation should be collected and compiled with utmost care.

Facilitation is a key aspect that has a direct impact on the effectiveness of the DISC exercise. Care should be taken in the selection of the facilitation team and training must be conducted well ahead of time.

The selection of services for assessment should be done carefully. Interface meetings and preparation of action plans must be undertaken in smaller groups with all relevant stakeholders involved. Having an unrelated audience of people who are not directly involved in the DISC process can lead to distractions and reduce the effectiveness of the overall exercise.

Input tracking is an important and essential step of DISC which should not be neglected or ignored while implementing DISC.

Training and actual implementation of DISC should not happen together. The two exercises should ideally be planned and implemented separately with a sufficient gap to allow stakeholders to understand and grasp the information shared with them. This will substantially help the exercise's quality of participation, interactions and action plan outputs. This time is also required for participants to organise, conduct orientations and complete the input tracking.

Training of OPD Members on the SDG/UNCRPD Framework in Odisha, Bengal (March, 2021)

Training of OPD members on the SDG/UNCRPD Framework in Odisha, Bengal. (March 2021)

Conclusion

The tool has undoubtedly shown potential to make a difference and compel services to be more inclusive. It brings attitudinal changes among all stakeholders and empowers them with knowledge and information.

The service providers understand their role and responsibilities better. Parents are better sensitised to not treat children with disabilities as a burden. People with disabilities and members of OPDs feel more empowered and self-confident. They realise the power of a collective approach versus an individual and fact-based method versus confrontational advocacy.

The pilot exercises have helped achieve the overall project objectives effectively. They have brought together service users and providers to jointly analyse issues related to education and Anganwadi services and to find collaborative ways to address these issues. It has empowered people with disabilities to know and claim their rights. Through DISC, people with disabilities have found a platform to gather and present evidence that can help drive objective decision-making without finger-pointing.

The DISC process is easy to follow and all necessary stakeholders can effectively participate and benefit from the exercise. It a gender-inclusive, disability-inclusive and constructive approach.

Resources for additional reading

Citizens Voice and Action -

www.wvi.org/meero/publication/citizen-voice-and-action-model

www.wvi.org/video/what-citizen-voice-and-action

https://gsdrc.org/professional-dev/citizen-voice-action/

Community Score Card -

https://care.org/wp-content/uploads/2020/05/FP-2013-CARE_CommunityScoreCardToolkit.pdf

www.participatorymethods.org/glossary/community-score-cards

www.kwantu.net/blog/2016/12/21/an-introduction-to-community-scorecards

www.action.org/resources/advocacy-toolkits

For those who are interested in knowing more about DISC can refer to the Programmer guide brought out by Sightsavers. To develop and collaborate around DISC, please contact Sightsavers India.

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