



FINDING SELF, LEADING OTHERS:

LEADERSHIP JOURNEYS
OF PERSONS WITH
DISABILITIES IN INDONESIA

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EXECUTIVE SUMMARY

KEY FINDINGS AND IMPLICATIONS

- Indonesian disability leaders' participation in the disability community is a key influence on how they lead.
- Families, friends and teachers, schooling experiences (positive and negative) and connections to the broader disability community support the leadership development of persons with disabilities.
- Interviewees identified authenticity, supporting others, and connecting with others to build awareness about disability and pursue change as key to effective disability leadership practice.
- Becoming a leader is a process, beginning at home with family and community, and involving opportunities to build skills, knowledge and confidence, as well as develop relationships and networks.
- Support for individual and collective leadership recognises that marginalisation and exclusion of persons with disabilities is a collective problem that needs to be addressed with collective approaches to change.
- Support for leadership development should focus on developing capacities inherent in everyone, not just on identifying those with 'leadership potential'.

THE IMPORTANCE OF DISABILITY LEADERSHIP FOR INCLUSIVE DEVELOPMENT

Persons with disabilities play an important role in driving inclusive development in Indonesia. At both national and local levels, disability activists have demanded legislative and policy change to bring Indonesia into line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and have been actively involved in efforts to develop new policies and laws. Organisations of Persons with Disabilities (OPDs) also play an important role in delivering services to persons with disabilities, including education and training, health and medical assistance, legal aid, and livelihoods support.

But persons with disabilities across Indonesia still face barriers to their full participation in society, politics and the economy. There are only a select few individuals and organisations involved in leading change, and they often operate with very little funding or other resources, particularly outside major cities. Building on what has already been achieved therefore requires investment in the individual and collective leadership capabilities of persons with disabilities.

WHAT IS LEADERSHIP?

Leadership can be understood as a process of influencing, guiding, motivating, or directing in which leader(s) and followers work together toward a common goal. This process is both social – because it involves people and how they interact with each other – and political – because it involves power, interests, agency and ideas. Because leadership is about relationships and influence, it is not the same as position.

Although leaders may be in formal leadership positions, they may also be someone who others turn to for advice or guidance, someone who has initiated change in their community, or someone who has been a role model for others.

Members of research team with staff from Puspadi Bali in front of the Annika Linden Centre in Denpasar



LEARNING FROM THE LIVED REALITIES OF LEADERS WITH DISABILITIES

Our research aimed to better understand how persons with disabilities lead efforts for social change in Indonesia, with a view to better supporting these efforts. We asked 55 disability leaders (26 women and 29 men) from both rural and urban areas across Indonesia to tell us about how they became a leader, how they understand leadership, how they see their role as leaders, and what they think their achievements are.

Most of the leaders we spoke to were founders or directors of established or young OPDs, but there were also artists, comedians, researchers, businesspeople, and public servants. The most experienced leader had been involved in the disability movement for 40 years, while the least experienced had been active for 4 years.

Our final sample included 55 disability leaders from 27 cities, towns, and districts across 9 provinces.

TABLE 1: INTERVIEWEES BY PROVINCE AND GENDER

Location	Female	Male	Total
West Sumatra	3	1	4
Jakarta Special Capital Region	7	6	13
West Java	3	6	9
Central Java	3	2	5
Yogyakarta Special Region	1	2	3
East Java	3	1	4
South Sulawesi	3	4	7
Bali	1	1	2
East Nusa Tenggara	2	6	8
Total	26 47%	29 53%	55 100%

DEVELOPING A 'POLITICAL' DISABILITY IDENTITY

Our research draws on the link between social identity and political behaviour. We use the idea of 'political disability identity' which connects people's self-perceptions and individual experiences with their identity as part of a group and with political action. Political disability identity is made up of a set of beliefs covering six domains: self-worth, pride, discrimination, common cause, policy alternatives, and engagement in political action.

Developing a political disability identity involves developing a sense of self-worth as 'a person who experiences disability' and as a member of the broader disability community. It also involves recognising that persons with disabilities have shared experiences of discrimination and that disability is a characteristic of the environment, not the individual. As a 'collective problem', disability needs to be addressed collectively and efforts for change directed at changing the social conditions that marginalise and exclude persons with disabilities. For people to seek this kind of change, they first need to identify as a member of the disability community and recognise that they share a common cause. They also need to believe that it is possible for individuals and groups to change the way things are.

FIGURE 2: DOMAINS OF POLITICAL DISABILITY IDENTITY



FINDING SELF

Our interviewees' life experiences led them to identify politically with their status as a person with a disability and to want to do something to change things for the better for all persons with disabilities. While interviewees' experiences were diverse, we identified several common aspects of their experiences. These included the importance of family members, friends and teachers in developing their self-esteem, offering advice and encouragement and providing early leadership opportunities. Positive educational experiences – as well as discrimination in school – and experiences which connected them to the broader disability community were also important in developing self-worth and pride as a person with a disability and recognising shared experiences of discrimination.

A female business owner shares her story



LEADING OTHERS

The disability identity that our interviewees' developed through their experiences shaped how they saw their role as leaders, what they understood to be the possibilities for change, and the choices they made about how to lead and what kinds of change to pursue. Our interviewees emphasised the need to be authentic in how they presented themselves as a way of modelling a positive disability identity to others. They saw their leadership role as being to develop others' sense that they could contribute to change by building their skills and confidence in their leadership ability. They also emphasised the importance of bringing people together, communicating ideas, and managing tensions and conflicts as an important part of how they led others.

Our interviewees saw discrimination and negative stereotypes as something that it is possible to change. An important focus for them was to build awareness of disability and change how people see persons with disabilities. They also worked collaboratively with other OPDs and policymakers with the aim of contributing to policy change.

TABLE 2: IMPACT OF LEADERSHIP JOURNEY ON LEADERSHIP PRACTICE

Domain of political disability identity	Link to leadership journeys	Impact on leadership practice
Self-worth	Developed through positive family and educational experiences and through becoming part of the disability community.	The choice to lead authentically as a way of modelling positive disability identity.
Pride		The strategy of empowering others as a way of demonstrating that their ideas and contributions are valued and developing their confidence and independence.
Discrimination	Often initially experienced at school.	Work undertaken by leaders to shift attitudes towards persons with disabilities.
Common cause	Identified through engaging with other persons with disabilities, often through OPDs, and through introduction to disability rights and the social model of disability.	The attention leaders gave to the relational and political work of bringing people together to pursue a common goal. The strategy of empowering others as a way of developing their leadership skills and sense that they can contribute to change as part of the collective.
Policy alternatives	Recognised through introduction to disability rights and the social model of disability, often through engagement in OPDs and with mentors.	The choice of policy and legislative change as a focus for collective advocacy efforts.
Political action		The strategy of empowering others as a way of building their capacity to lead future efforts for change. Collaboration with other OPDs and government actors to help drive reform of policies and practice.

IMPLICATIONS

Our findings highlight the importance of both the individual and the collective to disability leadership. This requires an approach to leadership development that builds the skills and capabilities of individual leaders, but with a view to the skills and capabilities of the group. The focus is therefore not on finding individuals with ‘leadership potential’ but on developing the leadership capacities inherent in everyone. It also requires attention to strengthening relationships and networks between OPDs and with government agencies and NGOs outside the disability movement.

For our interviewees, becoming a leader was a *process* that involved having many opportunities to better understand themselves, build their skills, knowledge and confidence, develop their relationships and networks, and learn from others. This finding highlights the importance of a ‘life course’ view of leadership development, which begins with experiences in the family and community and continues through school, tertiary education, civic organisations and the workplace.

Our findings suggest that strengthening disability leadership could usefully involve:

PROVIDING PERSONS WITH DISABILITIES WITH OPPORTUNITIES TO:

Develop self-worth and self-efficacy

Families and teachers play a critical role in developing self-worth and self-efficacy by ensuring that children with disabilities are included on an equal basis in family and school activities and encouraging them to develop independence. OPDs also support persons with disabilities to develop their self-esteem and independence – including through counselling and life-skills programs – and can provide spaces where persons with disabilities can meet and form friendships.

Develop their understanding of the social model of disability

OPDs play an important role in introducing persons with disabilities to the social model of disability and building their understanding of disability rights. This understanding is often a key motivation for people to become involved in efforts for change.

Build relationships and networks

Social organisations, activities and events focused on disability identity are important in building a positive disability identity and a sense of solidarity with the disability community. The relationships and networks created through these also provide leaders with resources, including access to individuals and organisations in other geographical areas or with different skillsets or knowledge. These are valuable for learning about new opportunities or strategies for change. They can also help build the collective power needed for social change to happen.

Learn by doing

Practical leadership experience – including being given opportunities to take on roles in organisations or lead activities – is critical to developing leadership skills and confidence. This experiential learning begins in families, schools and communities and continues in formal organisations and workplaces.

Learn from mentors

Mentors are a critical source of knowledge, skills and motivation for emerging leaders and provide important role models. Mentoring relationships are often informal and are developed through networks within the disability community.

PROVIDING CONSISTENT, LONG-TERM FUNDING FOR OPDS

OPDs are important vehicles for disability leadership. They help socialise emerging leaders into a political disability identity and provide valuable leadership experiences. Strengthening these organisations is therefore an important strategy for strengthening disability leadership, both individual and collective.

Reliable, long-term funding for OPDs can help them to plan longer term strategies for change and for developing their staff and organisational capacity. It can also free up the time of senior leaders within the organisation, allowing them to shift their focus from fundraising to investing in organisational development and nurturing junior staff and emerging activists in other organisations.

PROVIDING OPPORTUNITIES FOR ORGANISATIONS TO BUILD THEIR NETWORKS

Facilitating connections is a key strategy for strengthening the ability of disability leaders to work together for change. This involves providing opportunities for people to meet and work with others and to develop and strengthen relationships and networks.

Building networks is particularly important for organisations working in areas where OPDs are still developing, or in regional or remote areas. This can facilitate sharing of strategies and help strengthen the sense of solidarity and connection with the broader disability movement.



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