

## FINDING SELF, LEADING OTHERS:

LEADERSHIP JOURNEYS OF PERSONS WITH DISABILITIES IN INDONESIA

ELISABETH JACKSON, EKAWATI LIU, ISHAK SALIM, CUCU SAIDAH, JONI YULIANTO, NUR SYARIF RAMADHAN, YUYUN YUNINGSIH, ROBANDI, SURYA SAHETAPY, SEN SENDJAYA, ERIN WILSON

**MARCH 2023** 



The **Developmental Leadership Program** (DLP) is an international research collaboration supported by the Australian Government.

DLP investigates the crucial role that leaders, networks and coalitions play in achieving development outcomes.

dlprog.org dlp@contacts.bham.ac.uk @DLProg

Developmental Leadership Program International Development Department College of Social Sciences University of Birmingham Birmingham, B15 2TT United Kingdom

Cover photo: Atik Sulianami, Unsplash. All other photos courtesy of the research team.

#### ABOUT THE PROJECT

The research project, '<u>Disability leadership</u> in Indonesia' is a part of the Developmental Leadership Program, led by the University of Birmingham and La Trobe University and funded by the Department of Foreign Affairs and Trade (DFAT), Government of Australia [DLPGFA-A].

It looks at how people with disabilities can be supported to lead development and change. It asks:

- How has leadership of people with disabilities shaped local processes of change and development?
- What individual and broader social factors enable or constrain the ability of people with disabilities to be effective leaders in their communities?
- What interventions support people with disabilities to take on leadership roles or other positions of influence?"

Australian Aid

This publication has been funded by the Australian Government through the Department of Foreign Affairs and Trade. The views expressed in this publication are the authors' alone and are not necessarily the views of the Australian Government, the Developmental Leadership Program or partner organisations.









## CONTENTS

Key findings and implications	4
Introduction	5
Learning from the lived experiences of leaders with disabilities	6
Disability identity and leadership for social change	7
Our research	8
How do persons with disabilities become leaders?	12
Family foundations	12
Educational experiences	13
Becoming part of the disability community	16
How do disability leaders understand and practice leadership?	18
Leading authentically	18
Empowering others	19
Bringing people together	20
Shifting attitudes	20
Working with others	22
Conclusions and implications	24
References	29
Images	35

## **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'.

## INTRODUCTION

Persons with disabilities play an important role in driving inclusive development in Indonesia. At a national level, 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. This includes Indonesia's 2016 Disability Law, which incorporates an important shift towards a rights-based model, and a number of national government regulations and planning documents that flow on from this (Priebe and Howell, 2014; Nursyamsi et al., 2015).

n provinces, districts and cities across the country, persons with disabilities have been instrumental in advocating for new regulations, policies and plans on disability inclusion and supporting their development (Holden and Basjir, 2016; Afrianty, 2020). Organisations of Persons with Disabilities (OPDs)<sup>1</sup> 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 (Irwanto and Thohari, 2017; Dibley and Tsaputra, 2019; Salim, 2021).

Despite this, persons with disabilities across Indonesia still face significant barriers to their full participation in society, politics and the economy. The individuals and organisations involved in leading change are a select few, and often operate with very little funding or other resources, particularly outside major cities. Building on what has already been



1 Organisations of persons with disabilities (OPDs) are representative organisations that are governed, led and directed by persons with disabilities and whose staff are primarily persons with disabilities themselves (CRPD Committee, 2018; Disability Rights Fund, n.d). achieved will therefore require investment in the individual and collective leadership capabilities of persons with disabilities.

This paper sets out findings from a research study which aimed to better understand how persons with disabilities lead efforts for social change in Indonesia, with a view to better supporting these efforts.<sup>2</sup> It draws on in-depth interviews with 55 disability leaders (26 women and 29 men) from both rural and urban areas across Indonesia, exploring how their identities and life histories shape their understanding and practice of leadership. The paper begins by introducing the ideas around leadership and identity that have shaped the research. It then explains how the research was carried out, including how leaders were identified and selected, the locations that were chosen and how the data was analysed. The main section of the paper sets out the key findings around how persons with disabilities become leaders and how they understand and practice leadership. The paper concludes by outlining the implications of these findings for strengthening disability leaders and disability leadership.

## LEARNING FROM THE LIVED EXPERIENCES OF LEADERS WITH DISABILITIES

Half a decade after the adoption of United Nations Sustainable Development Goals, the need for - and value of - disability leadership is increasingly being recognised (see for example Guterres, 2022). Yet understandings of disability leadership have almost exclusively drawn on mainstream leadership models and on the experiences of disability leaders in the Global North.<sup>3</sup> Scholarship has also tended to focus on the barriers to leadership that persons with disabilities face (Marchioro, 2000; Hardy, 2021). As a result, we do not yet have a comprehensive understanding of how persons with disabilities - particularly in the Global South - understand leadership, how they become leaders, what motivates them to advocate for change, how they overcome challenges, and how best to support them.

Our research seeks to contribute to filling this gap by learning from the lived realities of Indonesian leaders with disabilities. Our hope is that this kind of experiential knowledge can enrich our understanding of disability leadership and leadership of social change more broadly. More practically, we hope that it can inform effective leadership development for persons with disabilities, which can can help strengthen their ability to lead their own movements for change.

The understanding of leadership that we apply in this study has been informed by the leadership studies literature and the literature on developmental leadership. In particular, we draw on relational views of leadership in which leadership is understood as a *relationship* between a leader/leaders and followers. Leadership involves a *process* of influencing, guiding, motivating, or directing in which leader(s) and followers work together toward a common goal (Rost, 1993, p. 102). This process is both social – because it involves people and how they interact with

<sup>2</sup> Ethics approval was obtained from Swinburne University Human Research Ethics Committee (later transferred to La Trobe University) in Australia. In-country approval for the research was obtained from Indonesia's National Research and Innovation Agency (*Badan Riset dan Inovasi Nasional*, BRIN).

<sup>3</sup> See for example Weeber (2004), Foster-Fishman et al. (2007), Caldwell (2010, 2011), Watanabe (2014), Vergara (2017), Gibney et al. (2021) and Harpur and Szücs (2022). For exceptions see Clifford et al. (2015), Majiet and Africa (2015), Kandasamy and Soldatic (2019) and King, Edwards and Watling (2021).

each other – and political – because it involves power, interests, agency and ideas (Uhl-Bien, 2006; DeRue and Ashford, 2010; Hudson et al., 2018). Being a leader involves 'claiming' this role – through how leaders present themselves and behave – as well as 'granting' or acceptance of the leader by others (Bartel and Dutton, 2001; DeRue and Ashford, 2010; Shamir and Eilam, 2005). Because leadership is about relationships and influence, it is not synonymous with position. Although leaders may occupy 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.

## DISABILITY IDENTITY AND LEADERSHIP FOR SOCIAL CHANGE

Leaders in the Global South are often members of social and political elites (see for example Sebudubudu, 2009; Brannelly, Lewis and Ndaruhutse, 2011; Schweisfurth et al., 2016; Spark, Cox, and Corbett, 2018). But how do leaders from minority groups, who do not enjoy many of the privileges that elites do – and indeed are often stigmatised in society – overcome barriers to help drive social change?

One way of understanding this is to focus on the choices that leaders make, how they use and grow the resources at their disposal and the leadership pathways they follow (Corbett, 2019). In this paper, we argue that the social identity of Indonesian disability leaders - as members of a disability community - is a key factor influencing the choices they make and the leadership pathways they follow. This identity is both personal and political and shapes how they see the world, what they understand to be the possibilities for change, and how they view their own role in bringing about change.

Our research draws on literature on the link between social identity and political behaviour. In particular, we use the idea of 'political disability identity' proposed by Putnam (2005) which connects people's selfperceptions and individual experiences with their identity as part of a group and with political action. According to Putnam (2005), 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 (see Figure 1).

Consistent with the social model of disability, 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 social, cultural, political, and spatial environment, not the individual.

As a 'collective problem', disability therefore needs to be addressed collectively and efforts for change directed at transforming the social conditions that marginalise and exclude persons with disabilities (Putnam, 2005; see also Scotch, 1988; Shakespeare, 1993; Dirth and Nario-Redmond, 2019). In addition to identification as a member of the disability community and recognition of a common cause, engagement in political action depends on a sense of individual and collective efficacy, that is, that it is possible for individuals and groups to change the status quo (Putnam, 2005; see also Little, 2010).

#### FIGURE 1: DOMAINS AND SUBDOMAINS OF POLITICAL DISABILITY IDENTITY

#### **SELF-WORTH** PRIDE DISCRIMINATION • Belief that persons experiencing • Claiming disability by acknowledging • Belief that people with disabilities are disability are of the same worth as oneself as a person with a physical or negatively stereotyped. mental impairment who experiences persons not experiencing disability. • Belief that persons with disabilities are disability. • Belief that persons with disabilities can typically treated differently (often be productive contributors to society. • Believing that disability is not unusual, negatively) in comparison to persons but rather is a common human · Belief that persons with disabilities are without disabilities. characteristic. undervalued in society. Belief that discrimination results in Believing that impairment is not inequality of opportunity and access to inherently negative but can become so social and economic resources. in certain cultural, social, and physical environments. • Recognising this characteristic as engendering membership in a cultural minority group. **COMMON CAUSE** ENGAGEMENT IN **POLICY ALTERNATIVES POLITICAL ACTION** • Belief that persons with disabilities • Belief that disability is not share similar experiences. characteristic of the individual. Belief that people experiencing disability are a political constituency · Belief that some of these experiences Belief that contributors to the disability should be modified or changed. experience can be identified and group. addressed. Belief that disability constituency • Belief that the contributing factors to groups represent political minority these modifiable experiences are similar. Belief that opportunities to reduce or groups. eliminate disability and to condition the • Belief that addressing them as a group disability experience are influenced by • Belief that engagement in political issue involves the development of a public policy. action by, for, and on behalf of that common politicl agenda. constituency group can effect policy change. Reproduced from Putnam (2005).

#### **OUR RESEARCH**

Our research approach reflects our view that persons with disabilities have a fundamental right to be engaged in a genuine way in research about disability issues. For this reason, six members of the team are persons with disabilities who themselves have a strong leadership identity and are influential within the Indonesian disability movement. This has allowed us to draw on their lived experiences to shape the research and interpret the findings. The remaining team members are researchers with an interest in disability leadership and inclusive development. Our approach to selecting people to take part in our study focused on identifying those who could provide us with rich information about the issues we were interested in (Patton, 1990). Our understanding of leadership as being about influence rather than (only) position led us to seek out both those with formal leadership positions within OPDs and those who were influential within the disability movement or seen as role models for persons with disabilities but not necessarily in a formal leadership position. We used a range of strategies to identify these individuals, including drawing on the team's own knowledge and networks, searching local newspapers and social media, and asking interviewees who they thought we should approach.

In addition to gender balance, we sought out both experienced and emerging leaders to enable us to capture the perspectives of people at different stages of their leadership journeys. To ensure some geographic diversity, we selected a mix of larger cities and smaller towns as well as some more rural areas. This enabled us to capture the perspectives of leaders in areas where the disability movement is well-established as well as those where disability activism is more nascent and there are fewer, smaller OPDs.

We included people with a range of different disabilities, including physical, sensory, neurological, and psychosocial disabilities. Our sample did not include any persons with intellectual disabilities and only one person with a psychosocial disability. The underrepresentation of persons with intellectual and psychosocial disabilities in leadership is a global phenomenon which may reflect 'a disability hierarchy' within the disability community or a view that persons with intellectual and psychosocial disabilities are more vulnerable or less capable of leadership (Foster-Fishman et al., 2007; Gibney et al., 2021).

Our final sample included 55 disability leaders from 27 cities, towns, and districts across 9 provinces (see map). Nineteen of them came from two of Indonesia's most densely populated cities: Jakarta and Bandung. Twenty-one came from regional cities and towns and urbanised districts (Solo, Makassar, Bukit Tinggi, Malang, Denpasar, Kediri, Bekasi, Kupang, Cirebon, Padang, and Yogyakarta) and the remaining 15 came from small towns and rural areas. Just under half of them (47%) were women (see Table 1). The majority of those 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.

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%

#### TABLE 1: INTERVIEWEES BY PROVINCE AND GENDER



Fieldwork was conducted in Indonesia between October 2021 and February 2022. The eight Indonesia-based members of the research team each took responsibility for one or more provinces, conducting in-depth interviews with 6-10 individuals, sometimes working in pairs. The dynamics of the COVID-19 pandemic meant that some interviews were conducted face to face, and others were conducted online or via telephone. Interviews averaged one and a half hours. All interviews were recorded and transcribed into Indonesian. Interviews with deaf persons were video recorded and then translated from sign language and transcribed into Indonesian. An interview guide was used to prompt discussions on the key topics, although interviews were allowed to evolve in line with the interviewee's responses. During interviews, we asked people to reflect on their leadership pathways, including important experiences and influential people, their understanding of leadership, how they practiced leadership, and what they thought their achievements were. These questions were informed by the literature on leadership development, particularly on how people develop an identity as a leader (Priest and Middleton, 2016; Epitropaki et al., 2016), the importance of experiences in childhood and adolescence to leadership development (Murphy and Johnson, 2011) and the meanings that leaders attach to key experiences in their lives (Shamir and Eilam, 2005; George et al., 2007). The research team's reflections on their own leadership journeys helped refine the questions.

To analyse the data, we developed an initial set of thematic codes based on our research questions which included the themes of 'understanding of leadership', 'pathways to leadership', 'factors supporting leadership development', 'barriers to leadership', 'leadership practices' and 'leadership successes and impacts'. As we read through the interview transcripts, we coded them according to these key themes, as well as identifying sub-themes. All team members were involved in coding the transcripts and identifying the key themes that emerged. As we wrote up the findings, we went back to the literature on disability leadership and social activism to identify how our findings resonated with similar studies and to develop a conceptual 'narrative' to connect our findings into a coherent whole. Drafts of this paper were shared among the team to validate the analysis and discuss practical implications.



## HOW DO PERSONS WITH DISABILITIES BECOME LEADERS?

or our interviewees, becoming a leader went hand in hand with the development of their identity as a person with a disability. While interviewees' experiences were diverse, we identified several common aspects of their life histories which contributed to their development as leaders. These included the importance of family members, friends and teachers in developing self-esteem, offering advice and encouragement and providing early leadership opportunities; the role of both positive and negative educational experiences in shaping disability identity; and the significance of experiences which connected them to the broader disability community.

These experiences contributed to interviewees developing self-worth, as well as enabling them to recognise the common cause they shared with other persons with disabilities. They were therefore foundational in the development of a political disability identity.

#### FAMILY FOUNDATIONS

Social networks – including families, friends, colleagues, and neighbours – provide important resources in the form of emotional and practical support (Rodriguez and Cohen, 1998). These not only fulfil basic social needs but also help people cope with challenges and achieve goals. Given the additional barriers that persons with disabilities face in their personal lives and careers, the support provided by social networks is particularly important (Liu, 2022; Chwalisz and Vaux, 2000; Putnam et al., 2003; Samosh, 2021).

For our interviewees, parents, spouses, siblings, children, and extended family members were a critical source of support, offering advice, encouragement, and comfort during difficult times, and supporting them to continue their education or seek out new experiences. They also provided practical support, including for schooling or medical treatment.<sup>4</sup> As one interviewee recalled:

My two uncles helped me so much, especially the one who was a school principal. My amputation made me feel inferior, but he encouraged me. He always sat me in the front row when I went to church. The front row is for important people, so maybe he wanted to boost my confidence. I didn't want to go to school, but he persuaded me. He's the reason I graduated from primary school and went on to high school.

"Parents, spouses, siblings, children and extended family members were a critical source of support."

4 Participants in Carter et al. (2011)'s study identified the important role of their families in having high expectations of them, providing advice and encouragement, connecting them to opportunities and experiences, and teaching them skills such as self-advocacy, choice making, and self-care.

Family members also supported interviewees to develop their self-worth and self-confidence, including by treating them as equal members of the family and teaching them to be independent.<sup>5</sup> As one interviewee explained:

In my family, I got used to being independent from a young age. There were a lot of weavers in my village, and before I went to school, I would work, spinning the thread and tying the material for weaving (ngelos kain dan menali bahan untuk tenun). I also cooked and worked in the garden by myself. I was expected to do things myself...

Parents and extended family members were therefore particularly important in developing the self-worth that is a key element of a political disability identity during childhood, including the belief that persons with disabilities are of equal worth to persons without disabilities and that they can make a productive contribution to their families and

#### EDUCATIONAL EXPERIENCES

Educational experiences - both positive and negative - played a key role in shaping interviewees' identity and their leadership pathways. Education is a key resource for leaders (Corbett, 2019). In addition to its intrinsic value, education can also signal credibility (Samosh, 2021) and provide access to further educational, employment and livelihood opportunities. While past research on developmental leadership has highlighted the importance of tertiary education for leaders in the Global South (see for example Brannelly, Lewis and Ndaruhutse, 2011; Jones, Jones and Ndaruhutse, 2014; Schweisfurth et al., 2016), for some of our interviewees, even obtaining a primary or secondary education was an

communities (Putnam, 2005). These positive experiences are significant given that home is not always a safe and inclusive place for persons with disabilities (Imrie, 2004). Persons with disabilities in Indonesia still experience isolation, rejection and even confinement (Minas and Diatri, 2008; Irwanto et al., 2010).

Strong social ties in the home environment have been found to support persons with disabilities to expand and benefit from wider social networks (Liu, 2022). Family members were also critical in developing interviewees' independence, contributing to their sense of autonomy. Both self-esteem and independence are important foundations for a sense of self-efficacy, that is, people's beliefs that they are capable of doing something to manage or control what happens around them. This in turn is an important factor shaping how leaders initiate action, approach challenging situations and respond to setbacks or obstacles (Paglis, 2010).

important achievement. In some areas, for example, having a disability made it difficult for interviewees to get to school or attend school consistently. As one interviewee explained:

I was 13 years old when I became a disabled person. In my first year of junior high school, I began to experience paralysis in my legs. At first, walking became more tiring, then I started stumbling and falling over a lot. I had to walk about 2 kilometres to school and back. The road was bad and there was no transport. For a couple of months, I forced myself to go to school, but it became more and more difficult. Finally, I gave up and quit school.

5 Samosh (2021) also finds that family members and friends treating persons with disabilities as equal was important for developing a positive disability identity, including self-acceptance, confidence and an understanding of disability as a 'neutral' characteristic of individuals.

Schools were often the first places where interviewees experienced discrimination or became aware of themselves as having a disability. As one interviewee recalled:

When I was at primary school, the principal would often call me to his office and say to me, "You shouldn't be at this school, you should be at a special school." Imagine saying that to a 7-yearold! I felt so hurt! But thank God I did well at school, so he let me stay.

Being refused entry to a mainstream school was a common experience for interviewees, particularly at high school level.<sup>6</sup> Interviewees also talked about experiencing bullying and discrimination from both teachers and students:

I was the only one with a disability in my public primary school and my own homeroom teacher discriminated against me. Back then, students sat on benches at school, and I was the only one who wasn't given a bench. I had to sit on the ground in the dirt which made it difficult to write. This went on for a couple of days. Then I told my father, and he was so angry at the school. He reported it to the principal and the principal reprimanded my homeroom teacher. From that day I was treated as special at school.

In some cases, these negative experiences had positive outcomes, such as when interviewees responded to discrimination by becoming more determined to prove that they were capable and 'belonged' academically in the school.

Others spoke with pride about how they had successfully challenged discriminatory practices or policies and been accepted into mainstream schools.<sup>7</sup> This helped develop valuable self-advocacy skills, which can provide a foundation for collective advocacy (Dirth and Nario-Redmond, 2019). It also enabled interviewees to continue with their schooling and achieve better educational outcomes than they otherwise would.

Family members were particularly important in advocating for interviewees, encouraging them to continue their schooling or ensuring they were able to get to school. Interviewees gave examples of principals or teachers providing encouragement and recognising their academic potential.<sup>8</sup> One interviewee explained that a teacher encouraged her to continue her schooling after she had dropped out because of her physical disability:

My parents didn't realise I didn't want to go to school anymore. I just said I had an upset stomach. I was selling [homemade] fried snacks from home and earning a lot of money. Then the principal came to our house looking for me. When I said I had to work so my siblings could go to school he gave me a full scholarship. It was a private school, but he promised I wouldn't have to pay anything. The scholarship meant I didn't feel like I was a burden to my parents, so I went back to school.

- 7 Carter et al. (2011) find that academic success was important in helping young people with disabilities recognise their leadership potential.
- 8 Carter et al. (2011) also find that for young people with disabilities teachers and other school staff are important in providing information and access to opportunities, offering encouragement and support, and advocating on behalf of the student to be included in challenging coursework and extracurricular activities.

<sup>6</sup> This reflects social stigma around disability, which means many people see persons with disabilities as not 'belonging' in mainstream schools. It also reflects the limited understanding of different disabilities and of inclusive teaching practices among teachers, which means schools and teachers often do not feel equipped to teach students with disabilities.

Teachers also provided early leadership opportunities and experiences. These were important in building interviewees' belief in their own capabilities and sense of responsibility, as well as providing experience of organisational life. This often began in primary school, where interviewees described being given responsibilities as class leaders, sporting team captains, or student representatives in their schools. As one interviewee recollected: "At school I was always a group leader. The teacher had faith in me, and that made me confident." Another said:

Because I was tall, I was chosen to join the flag raising troop when I was in primary school. In the beginning, they put me towards the back, but my marching was always out of sync with everyone else because I couldn't hear the instructions. At first the teacher didn't know what to do. Then she decided I should be the captain, so I was out the front, shouting out instructions and everyone marched in time. I was also the captain of the volleyball team. On the volleyball court, I directed the team, told them their positions. [From these experiences] I learned responsibility.

Religious organisations and other civic organisations also provided early leadership experiences. These were important in helping interviewees – and others – recognise their strengths and leadership potential. As one interviewee recalled:

I was active in the mosque youth organisation in my village and whenever there was conflict, I was always the one asked to mediate. One time there was a conflict with the neighbouring village, and I was the one asked to lead the delegation. Another said:

I was 11 years old and attending a Catholic boarding school. The nuns appointed me as Head girl in my dormitory. I became a leader because it was easy for me to communicate with other deaf children who were older and bigger than me... to make sure they followed the rules for the dorm and completed their homework.

Positive educational experiences were therefore important in further developing interviewees' confidence and self-esteem, building their skills in self-advocacy, and helping them begin to see their leadership potential. These experiences contributed to their sense of self-worth as a person with a disability. However, interviewees also experienced educational discrimination.

While acknowledging the negative impact of such discrimination, these personal experiences of stereotyping, being treated differently, and not having access to the same educational opportunities were nonetheless foundational in the development of interviewees' beliefs about discrimination and their growing political disability identity.<sup>9</sup> These experiences were particularly important as interviewees began to look beyond their own experiences to the shared experiences of the disability community.

"Positive educational experiences were important in developing interviewees' confidence and helping them begin to see their leadership potential."

<sup>9</sup> Caldwell (2010) finds that the leadership journeys of leaders with developmental disabilities are often founded on experiences of discrimination in schools.

### **BECOMING PART OF THE DISABILITY COMMUNITY**

For many interviewees, meeting other persons with disabilities – for example through online disability groups, forums or national and international events – was a critical point in their leadership journey. It enabled them to form friendships and develop self-awareness and self-confidence.<sup>10</sup> Importantly, it also helped them feel connected to – and part of – the disability community.

For one interviewee from a small town in West Sumatra, the experience of attending one of the government vocational training centres for persons with disabilities gave her a sense of solidarity with the disability community, as well as supporting her personal development:

I'm so grateful I was able to get out of my village and have that experience at Cibinong. People came from all over Indonesia, and we mingled together for those 10 months. Our mentality was honed, our personality was honed, it was basically all about self-discipline.

Many interviewees also connected with other persons with disability by becoming involved in OPDs. For some interviewees, this went hand in hand with 'claiming' their identity as a person with a disability:

When and why I got involved in the [disability] movement... it started with accepting myself as a blind person. When I realised that my eye disease couldn't be cured, I started to become more selfaware, to think about how I would fulfil my own rights, be able to go to school, work, play, have friends, engage with other people, and so on. For others, it helped them to see beyond their own experience and recognise that they had something to offer others. As one interviewee said:

Joining [local OPD] prompted me to think about what I could do, and my mindset changed. From seeing myself as alone, a victim, to thinking about what I can do to help others. Bit by bit I recognised my own potential.

#### Another reflected:

"I decided that as a person with a disability I have to be seen as someone who contributes to society or to the community. That's my biggest motivation, that persons with disabilities can play a role in society."

OPDs were also important in building interviewees' understanding of disability. In particular, involvement in OPDs introduced interviewees to the social model of disability and to the idea of working collectively to pursue disability rights.<sup>11</sup> As one interviewee recollected:

After I finished my undergraduate degree, I tried to get a job – as is my right – but it wasn't easy. I realised that I couldn't do it on my own. Then I found out about OPDs like [national OPD]. I learned so much, and that's when I started to get involved in the movement. I realised that if we work together so everyone can enjoy their rights, then my rights will also be fulfilled. That's made me strong in so many ways, both directly and indirectly.

11 Little (2010) finds that disability organisations are a key forum for building persons with disabilities' understanding of the social model of disability.

<sup>10</sup> A number of studies find that involvement in clubs and community activities and events – including those which are disability specific – are important in developing self-worth and confidence among persons with disabilities (see for example Putnam et al., 2003; Weeber, 2004; Carter et al. 2011; Caldwell, 2010, 2011; Samosh, 2021).

Becoming involved in OPDs was therefore a key point in interviewees' leadership journeys and a key contributor to the development of their political disability identity. In addition to further developing their sense of pride as a person with a disability, these experiences were a catalyst for recognising a 'common cause' (Putnam, 2005).

Involvement in OPDs helped interviewees to see that their experience of disability was one that others shared and that they were part of a broader disability community. It was also the point at which many interviewees began to realise that they could address these shared challenges by working together. These are all important first steps towards collective action for change (Klandermans, 1997; van Zomeren, Postmes and Spears, 2008 cited in Nario-Redmond, 2020; Schur, 1998; Nario-Redmond et al., 2013; Nario-Redmond and Oleson, 2016).

Involvement in OPDs also provided important resources which supported interviewees' leadership development. This included opportunities to learn how organisations work and to build skills in engaging with government and donors, as one interviewee recalled:

I was appointed to the committee of the [district] branch of [national OPD] in mid-1998. I was still in junior high school .... [B]efore I knew it, I was appointed as the branch chair and the treasurer. I had no idea what I was doing but the other committee members helped me out and I learned from them.

Involvement in OPDs also developed interviewees' relationships and networks with other disability activists, as one interviewee reflected, "I was active in a local NGO. Through that organisation, I developed my networks with other disability activists ..." These relationships and networks provide access to information and opportunities for learning about others' strategies and tactics for driving change. They also provide a network of potential collaborators in social change efforts.

Finally, OPDs provided access to advocates and activists who acted as mentors. These mentors gave advice and served as a sounding board for discussing ideas around disability rights. They motivated interviewees to become involved in the disability movement and provided opportunities that helped build interviewees' skills in managing organisations. They were also role models, offering an example of what persons with disabilities can achieve.<sup>12</sup> As one interviewee explained:

In the past, I didn't have much confidence, and I used to feel stupid. [Disability activist] said I shouldn't be indecisive. At first, I didn't understand why she said that. Then when I looked at her, I saw that she was firm, to the point. Some people even saw her as fierce. It's better to be like that. From that time, I started to change, thanks to her. [Disability activist] helped me a lot in becoming a good leader.

#### Another recalled:

[Disability activist] was really supportive. He was my teacher in becoming a leader. A few times when I thought I couldn't do something, he said 'Just give it a go'. The opportunities he gave me have made me strong."

<sup>12</sup> Both Carter et al. (2011) and Samosh (2021) find that having a mentor or role model with a disability are valuable in developing leadership skills among persons with disabilities.

## HOW DO DISABILITY LEADERS UNDERSTAND AND PRACTICE LEADERSHIP?

he 'political disability identity' that interviewees' developed through their experiences in their families, in education and in OPDs shaped their understanding and practice of leadership in several ways. Reflecting the importance of self-worth and pride, interviewees emphasised the need to be authentic in how they presented themselves as a way of modelling a positive disability identity to others. In recognition of the need to work collectively in pursuing change, 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 emphasised the importance of bringing people together, communicating ideas, and managing tensions and conflicts as part of their leadership practice. Their belief that discrimination and negative stereotypes can be addressed led them to use several different strategies to reshape the discourse around disability as a way of building awareness and changing public perceptions. They also proactively sought to develop collaborative relationships with other OPDs and policymakers with the aim of effecting policy change.

### LEADING AUTHENTICALLY

When we asked interviewees how they understood and practiced leadership, many emphasised the importance of being selfaware and leading by example.<sup>13</sup> This included ideas around self-reflection, understanding your own strengths and weaknesses and becoming your true self.

As one interviewee stated: "For me the main thing is my own character, because I have to be an example. ... I have to demonstrate what I'm saying through my actions." Another said: "I've realised that being a leader means you have to know yourself first. Otherwise, how can you lead others? I think you need to start by leading yourself."

Becoming self-aware required them to engage in ongoing learning, including learning from others, and seeking feedback from those around them. One interviewee felt that leaders "...shouldn't be shy about learning from others. Even those who are new [to an organisation] have something we can learn from". It also required them to be "humble" and to "control their ego". A number of interviewees spoke about the importance of leaders being committed, principled and firm while still able to be flexible and to compromise when this was needed. And although interviewees emphasised the need to listen to and accommodate others' views, they recognised

<sup>13</sup> Participants in Carter et al. (2011)'s study also identified 'leading by example' and providing a positive role model for others as important aspects of leadership for young people with disabilities.

that no decision would please everyone, as one interviewee explained: "I listen to everyone, but my attitude is that people will always criticise a decision, so it's just a matter of choosing who criticises you."

These reflections are consistent with notions of 'authentic leadership'. Authentic leaders are focused on acting in accordance with their 'true self'. This requires them to have a strong sense of their identity, beliefs and values and to be open with others about their motives, goals, and shortcomings. In being their "true selves", authentic leaders can encourage others to reciprocate (Luthans and Avolio, 2003; Gardner et al., 2005; Avolio and Gardner, 2005 cited in Procknow, Rocco and Munn, 2017).

Our interviewees' choice to lead in an authentic way can be seen as a way of expressing pride in their disability identity and modelling this to others. This kind of 'indirect mentorship' (Foster-Fishman et al., 2007) in which persons with disabilities demonstrate confidence and conviction in their leadership is particularly important given the significance of positive role models to interviewees' own leadership development. Disability leaders' modelling of characteristics such as humility, commitment to a cause, and principled behaviour is also part of the relational process of influencing, guiding or motivating followers as they work towards their common goal.

"A second important role that interviewees saw for themselves was in empowering those they lead."

### **EMPOWERING OTHERS**

A second important role that interviewees saw for themselves as leaders was in empowering those they lead. As one interviewee explained: "I don't practice the old model of leadership. It's more about giving opportunities to others, because I believe that if others succeed then I succeed too." Another said: "I see successful leadership as being when people leave my organisation and set up a new organisation with a new vision, when they become leaders themselves." This was linked to the view that leadership is not a characteristic or quality that only a few people possess. Instead, as one interviewee explained: "Leadership is something that everyone has ..."

This view of leadership as being concerned with empowering others was reflected in how interviewees described their leadership practice, as one interviewee explained: "I don't think of myself as a leader. I think of myself as a 'supporter'."

Interviewees highlighted the importance of encouraging others to share their opinions, listening to what others have to say, providing others with opportunities, trusting them with additional responsibilities, and providing mentoring, guidance and advice. This aimed to support others to 'learn through doing' and build their confidence in their leadership abilities. As one interviewee said:

My motto is to help persons with disabilities in any way I can so they can be physically and economically independent. We've also started to do this by recruiting persons with disabilities as staff. They learn from the beginning, [about] management, English, communication.... The most important thing is leadership experience, so we give them challenges, small projects that they can develop and manage themselves. Only if they are given opportunities can they grow and develop. The process of learning how to be responsible is important. Empowering others often required leaders to make a conscious choice to 'step back', as one interviewee explained:

As leaders, we need to have the selfawareness to realise that we are not the only ones who lead, and the awareness to encourage others - especially those from marginalised groups - to speak up. I think that's one of the essential criteria of a leader.

By empowering those they lead, interviewees therefore sought to develop others' skills and confidence in their leadership capacity, demonstrate that their ideas and perspectives are valued, and build their sense that they can contribute to change. This not only strengthens the personal efficacy of individuals, it also develops the collective efficacy of the disability community to drive efforts for change.

#### **BRINGING PEOPLE TOGETHER**

Many of our interviewees highlighted the fact that working with others was key to making a difference. Within their own teams, they emphasised the need to recognise and value the different and complementary skills and knowledge that others had and proactively draw on these in working together towards change. As one interviewee explained: "I'm not strong enough on my own. In this leadership position, I'm mostly leading from behind, supporting others. I'm not above anyone else. I don't give them orders. We're equal and we work together."

For our interviewees, leading efforts for social change involved being able to 'bring people together' behind a common cause and supporting them to work together productively and harmoniously. This requires leaders to use a range of skills. Many of our interviewees felt that a key aspect of their role was explaining ideas, sharing new ideas and using ideas to influence people. They also felt that communication and listening skills were important, as was being able to mediate differences of opinion and conflict when these occurred, "connect people" and "have strategies to accommodate a variety of characters and interests". Navigating these relational dimensions of leadership was often the most difficult part of being a leader, as one interviewee explained:

Sometimes in organisations there is a mixture of young people, older people, people from the private sector, civil servants, farmers. Bringing all these people together is really difficult, especially if there are people who feel they know better because they're older... I don't want to use the term 'battle for authority'... but if there are lots of people with different views, bringing the organisation or community together is a real challenge.

These reflections demonstrate the significant effort that interviewees put into aligning the interests of those within and outside their organisations and persuading them to work together towards a common goal. This stems from the belief that addressing the 'common cause' involves developing a 'common political agenda' (Putnam, 2005) and is part of the essential relational and political work of leading collective efforts for change, involving 'trust-building, negotiations and bargaining' (Hudson et al., 2018; Nazneen, 2019).

### SHIFTING ATTITUDES

A core belief underpinning political disability identity is that discrimination towards persons with disabilities is rooted in negative stereotypes and that these can be addressed (Putnam, 2005). This view was evident among our interviewees, many of whom saw their role as building others' awareness about disability and changing perceptions of persons with disabilities. As one interviewee explained, "spreading the issue of disability to many people... that's how change happens." Interviewees described a range of ways in which they sought to raise awareness and change perceptions of disability. For some, this involved demonstrating that persons with disabilities are capable through their own example. As an interviewee from a regional area in Eastern Indonesia explained:

People here don't understand about inclusion. ... They still say [persons with disabilities are]'defective' (*cacat*). So I introduce them to it. I show them through what I do. And then they realise 'Oh, even though [persons with disabilities] have limitations, they can still do things.'

For others, the language they used to frame the issue was central to their strategy for changing attitudes. As one interviewee explained:

When I do advocacy, I know that it's more effective to use the word 'discrimination'. It hits people in the heart. When I say, "This is discrimination", people immediately realise and want to change their minds. They try to explain that they didn't mean to discriminate and clarify what they really meant. So, the word discrimination can be seen as my strategy... I used to use the word 'unjust', but I felt it wasn't strong enough. The word 'discrimination' has a stronger effect, as does the word 'rights'. It's turned out to be effective.

Another drew on the concept of *bhinneka tunggal ika* (unity in diversity) to make the argument for disability inclusion. This concept is central to Indonesia's national identity and is intended to reflect the fact that the Indonesian nation is inclusive of diverse ethnic groups, languages, cultures, religions, and beliefs. When we talk about social inclusion, we already have the term *bhinneka tunggal ika* [unity in diversity]. How does the issue of disability fit into this? ... The language of inclusion is the language of programs or projects. But when we talk about *bhinneka tunggal ika*, it's a matter of ideology... [Social inclusion] already has a home in *bhinneka tunggal ika*, but how do we pull other issues into it.

Other interviewees used their art practice to raise awareness about disability issues. One interviewee with a psychosocial disability who is a visual artist explained:

I started using my art to advocate for mental health issues in the national media in 2012... We have the same rights as others. We have the right to an opinion. We have the right to fair and equal opportunities, and we also have the right to speak, to be heard, to create. That's actually what I want to say [through my art].

Another used the medium of stand-up comedy to draw attention to disability issues:

I've actually been an activist advocating for disability for quite a while, since the early 2000s and I'm still active in the disability movement. But around 2008 to 2010 I started to feel a bit fed up that we were just doing the same old advocacy, meeting with the parliament, meeting with government officials, meeting with other stakeholders, and always in a serious context... Then I came across stand-up comedy and I felt like this was an art form that would give me a wider audience for promoting awareness raising... He saw this as an alternative form of advocacy, which complemented other approaches:

Getting into stand-up comedy was actually my strategy for collective leadership, a strategy for 'attacking' from all directions. Advocacy is fine, it's necessary. Meeting and chatting with the parliament and the President are necessary ... But if our goal is recognition of rights then we need leaders 'attacking' all sectors ... This is a long-term effort, and in my view the challenge is coordinating with each other... to connect the efforts of all the leaders so that [the movement] is sustainable. That's what I see as our main homework.

Interviewees therefore took different approaches to framing the issue of disability inclusion and different approaches to sharing their ideas. Their reflections suggest that these are deliberate strategies that they have chosen as a way of shaping the narrative around disability inclusion as well as to 'legitimise their claims, convince policymakers and garner wider public support' (Nazneen, 2019, p. 26; Hudson et al., 2018).

"Interviewees described a key part of their role as building networks or relationships with other OPDs."

### WORKING WITH OTHERS

A strong theme throughout the interviews was the importance of working with the broader disability community to address the 'collective problem' of discrimination and exclusion. As one interviewee stated:

I've found that it's very difficult to get things done on your own. But when you're part of the right community, you can do things. To be able to compete with 'normal' people, we need to unite and work together.

In recognition of this, interviewees described a key part of their role as building networks or relationships with other OPDs. However, they also felt that working with actors outside the disability movement – including government agencies and civil society organisations – was critical, particularly when they sought broader social change, beyond their specific issue or local area.

Policy and legislative change was an important focus for collective advocacy efforts. This reflects the view that public policy is an important influence on the disability experience and that political action is necessary to achieve policy change (Putnam, 2005). An interviewee who was involved in the drafting of Indonesia's 2016 Disability Law felt that this significant legislative reform was possible in part because national OPDs had worked together in a unified way, and consulted widely with local-level OPDs: "When we were drafting the Disability Law, we were all united, we had one voice ... I see that as the peak of disability organisations' unity."

Collaboration with others often developed over time, with relationships built through practical experiences of working together on real problems. As one interviewee explained:

As a network we collaborated with the South-Central Timor district parliament and others and that resulted in our district having Regional Regulation No. 5 of 2020 [on disability rights]. Following that we cooperated with [provincial OPD] on the East Nusa Tenggara regional regulation on empowerment of persons with disabilities.

Interviewees rarely described taking confrontational approaches in seeking policy change. Instead, they sought to build relationships and trust with national and local governments by providing them with input and constructive feedback on issues relating to disability. Over time, this meant that government called on them more often. As one interviewee explained:

During the [2018] Asian Para Games we were involved in providing training for volunteers... Since then, other government agencies have also engaged with us, even if it's just sharing [our perspectives]. In terms of longer-term collaboration, its mostly with the Jakarta Provincial Government. The Governor has mandated that facilities the provincial government manages have to be more accessible, so I've been involved in that, meeting with mayors in Jakarta, going to their offices to check accessibility and have discussions.

#### Another said:

More recently, in addition to our regular programs, we have been carrying out research, advocacy, and other activities in partnership with the government and the community. One of our big wins has been the issuing of regional regulations [on disability rights] for West Sumatra and Padang... We were involved in that process... Now we're involved in lots of other activities in Padang around inclusive education, inclusive disaster risk reduction, workers with disabilities, [and] inclusive planning and evaluation.

These reflections suggest that one source of legitimacy for disability leaders is as 'experts' on disability inclusion, based on their lived experience. As interviewees attest, this has given them credibility and an ability to represent the interests of the collective in policy discussions (Nazneen, 2019, p.14).



## **CONCLUSIONS AND IMPLICATIONS**

Our interviewees' life experiences – in their families, in schools and in OPDs – led them to identify politically with their status as a person with a disability and to want to do something to change social conditions for all persons with disabilities. This political disability identity 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 (see Table 2). 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 (see also Foster-Fishman et al., 2007). It requires attention to strengthening relationships and networks between OPDs and

Domain of political disability identity	Link to leadership journeys	Impact on leadership practice
Self-worth Pride	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. 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	The choice of policy and legislative change as a focus for collective advocacy efforts.
Political action	rights and the social model of disability, often through engagement in OPDs and with mentors.	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.

#### TABLE 2: IMPACT OF LEADERSHIP JOURNEY ON LEADERSHIP PRACTICE

with government agencies and NGOs outside the disability movement. Strengthening disability leadership therefore involves different entry points (at different times in people's lives) and at different levels (individual and collective).

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. These opportunities often built on each other, such that initial opportunities and experiences opened up further opportunities and experiences. 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 (Foster-Fishman et al., 2007).

Our findings suggest that strengthening disability leadership could usefully involve:

## PROVIDING OPPORTUNITIES FOR PERSONS WITH DISABILITIES TO:

#### Develop self-worth and self-efficacy

Political disability identity is founded on a positive sense of self and pride as a person with a disability. During childhood and early adulthood, families and teachers play a critical role in this by ensuring that children with disabilities are included on an equal basis in family and school activities. Friends and peers are also central, so encouraging children and young people to develop friendships with others with and without disabilities is important.

Families and teachers can also educate children and young people about their disability and encourage them to discuss their thoughts, feelings, and experiences. This can support them to develop a positive sense of self as well as helping them to better understand themselves and their needs, providing a foundation for self-advocacy (Smith and Mueller, 2022). Another role for families and teachers is encouraging children and young people to develop independence by teaching them essential life skills. This can help build a sense of personal efficacy, an important foundation for both life and leadership.

Given that not all families and schools provide these experiences, there is an important role for OPDs and other service providers in supporting persons with disabilities to develop their self-esteem and independence, including through counselling and life-skills programs. OPDs can also provide spaces and fora where persons with disability can meet and form friendships.

The importance that interviewees ascribed to leading authentically also suggests that there is value in providing ongoing opportunities for persons with disabilities to reflect on their selfperceptions, values, beliefs and personal goals, including through leadership development programs run by OPDs or other organisations.

## Develop their understanding of the social model of disability

An important element of political disability identity and a key motivation for collective efforts towards social change is the recognition that persons with disabilities face common challenges and that this is the result of the social, cultural, political, and spatial environment. For our interviewees, this recognition often came when they were exposed to the social model of disability through their involvement in OPDs and interactions with disability activists and leaders. While this often takes place during early adulthood, there is significant value in families and teachers introducing persons with disabilities to these ideas during their primary and secondary school years. This can help provide the foundations for developing an understanding of disability rights.

However, given that many persons with disabilities "are not socialised into a disability identity by their families, schools and communities" (Foster-Fishman et al., 2007), OPDs continue to play an important role in this socialisation process, as our interviewees attested.

While this often happens organically, one example of a more deliberate effort is an initiative called the Education and Advocacy Movement for an Inclusive Indonesia School (Sekolah Gerakan Pendidikan dan Advokasi Indonesia Inklusif (Gradiasi)) which began in 2018 and in which several members of the research team have been involved.<sup>14</sup> A 10 day foundational course takes emerging activists through a staged process, building self-awareness and self-acceptance and introducing them to key ideas and concepts around disability and disability rights. Case studies from the national and local levels build participants' knowledge of approaches to community organising and policy advocacy. The course is led by experienced activists and a key focus is on supporting emerging activists from regional areas to build their skills and knowledge ('Menciptakan aktor difabel', 2019; 'Sekolah Gradiasi dan harapan', 2020; 'Pendaftaran Sekolah Gradiasi', 2020). While donors have played an important role in supporting disability activists to initiate this course, there is a role for the Indonesian government in funding this and similar initiatives to ensure it is sustainable.

#### **Build relationships and networks**

Our findings reinforce the importance of involvement in social organisations, events and activities for the self-esteem of persons with disabilities. While social engagement in general has been found to have benefits (Putnam et al., 2003; Carter et al., 2011), social organisations, activities and events that make disability identity more salient are particularly important in building a positive disability identity and a sense of solidarity with the disability community (Nario-Redmond, 2020).

Relationships and networks also provide leaders with resources – including access to individuals and organisations in other geographical areas or with different skillsets or knowledge – which they can use to learn about new opportunities or effective change strategies and help "build the collective power needed for social change to happen" (Foster-Fishman et al., 2007).

Persons with disabilities should therefore be encouraged - including by their families and teachers - to join OPDs and take part in disability community activities and events. Donors and other development actors can provide practical support by working with the disability community to organise or fund disability community groups and events.

"Donors and other development actors can provide practical support by working with the disability community to organise or fund disability community groups and events."

<sup>14</sup> The initiative was initially funded through Program Peduli, implemented by The Asia Foundation and funded by the Australian Department of Foreign Affairs and Trade.

#### Learn by doing

Our interviewees highlighted the importance of practical leadership experience – including being given opportunities to take on roles in organisations or lead activities – as critical to developing their leadership skills and their confidence in their ability to lead (see also Foster-Fishman et al., 2007). This experiential learning begins in families, schools and communities and continues in formal organisations and workplaces.

Mentors play a particularly important role in creating opportunities for experiential learning. Good mentors also create an environment where emerging leaders feel 'safe' asking for help and making mistakes. They act as a sounding board for ideas and strategies, talk through challenges, and prompt reflection on successes and failures. In addition to mentors, OPDs, NGOs, businesses, and government agencies could create opportunities for learning by doing through offering internships, organisational placements, volunteering, or job shadowing. Small grants from donors or local governments for community-based initiatives could also provide an opportunity for emerging leaders to practice their leadership skills (see Jackson et al., 2021).

#### Learn from mentors

Mentors are a critical source of knowledge, skills and motivation for emerging leaders and provide important role models. For most of our interviewees, these were informal relationships developed through networks within the disability community. Our findings suggest that senior disability activists have an intrinsic motivation - linked to their disability identity - to mentor and empower others. We therefore do not necessarily advocate for formalising mentoring arrangements. Rather, we suggest below that providing consistent core funding for OPDs can provide senior activists with the time and space they need to devote to mentoring others. We also suggest that creating more opportunities for persons with disabilities to meet and develop their relationships and networks can open up access to potential mentors.

## Providing consistent, long-term funding for OPDs

Our findings indicate that OPDs are important vehicles for disability leadership, helping socialise emerging leaders into a political disability identity, providing valuable leadership experiences, and serving as a source of mentors. Strengthening these organisations is therefore an important strategy for strengthening disability leadership, both individual and collective.

Most OPDs in Indonesia are run on a volunteer or semi-volunteer basis: very few receive adequate or consistent funding for their staff or programs (PNPM Special Program on Disability, 2015).<sup>15</sup> 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.

The type of funding also matters. As with funding of civil society organisations more generally, funding for OPDs – either from international donors or government agencies – is often for projects or activities that are driven by the funder's agenda, rather than the agenda of the organisation itself (McLeod, 2021; Davis, 2015). In contrast, funding for core staff and organisational functions can help put power back in the hands of disability leaders themselves.

15 This is the case for the Indonesian NGO sector more broadly (Davis, 2015).

## Providing opportunities for organisations to build their networks

Given interviewees' view of leadership as a collective effort and engaging with other people and organisations as critical to success, facilitating connections is a key strategy for strengthening disability leadership. This involves providing opportunities for people to meet and work with others and to develop and strengthen relationships and networks.

Networks are particularly important for organisations working in areas where OPDs are still developing, or in regional or remote areas. Interviewees from these areas emphasised the importance of hearing about what was happening in other areas and learning from other leaders. This not only facilitated sharing of strategies, it helped strengthen their sense of solidarity and connection with the broader disability movement. Some interviewees also mentioned the importance of international connections in this regard.

It is important to note that relationships and networks cannot be 'forced'. Past donor efforts to 'create' coalitions within the disability movement in Indonesia have largely failed, and in some cases caused further discord. A more appropriate role for donors is to provide opportunities where organisations can identify common interests and collaborate on their own terms.



## REFERENCES

Afrianty, D. (2020). The role of disabled people's organisations in promoting the CRPD in Indonesia. In E. Kakoullis and K. Johnson (Eds.), *Recognising human rights in different cultural contexts*, (pp. 333–352). Palgrave Macmillan.

Avolio, B.J., and Gardner, W.L. (2005). Authentic leadership development: Getting to the root of positive forms of leadership. *The Leadership Quarterly*, 16(3), 315-338.

Bartel, C., and Dutton, J. (2001). Ambiguous organizational memberships: Constructing organizational identities in interactions with others. In M.A. Hogg and D.J. Terry (Eds.), *Social identity processes in organizational contexts*, (pp. 115-130). Psychology Press.

Brannelly, L., Lewis, L., and Ndaruhutse, S. (2011, November). Learning and leadership: Exploring the linkages between higher education and developmental leadership (Research Paper 18). Developmental Leadership Program. <u>https://www.dlprog.org/</u> <u>publications/research-papers/learning-and-</u> <u>leadership-exploring-the-linkages-between-</u> <u>higher-education-and-developmental-</u> <u>leadership</u>

Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, 54(11), 1004–1014. Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, 49(5), 315–326.

Carter, E.W., Swedeen, B., Walter, M.J., Moss, C.K., and Hsin, C.-T. (2011). Perspectives of young adults with disabilities on leadership. *Career Development for Exceptional Individuals*, 34(1), 57–67.

Chwalisz, K., and Vaux, A. (2000). Social support and adjustment to disability. In R.G. Frank and T.R. Elliott (Eds.), *Handbook of rehabilitation psychology*, (pp. 537–552). American Psychological Association.

Corbett, J. (2019, September). Where do leaders come from? A leader-centred approach. Developmental Leadership Program. <u>https://</u> www.dlprog.org/publications/foundationalpapers/where-do-leaders-come-from

CRPD Committee (2018). General comment on article 4.3 and 33.3 of the Convention on the participation with persons with disabilities in the implementation and monitoring of the Convention.

Davis, B. (2015). Financial sustainability and funding diversification: The challenge for Indonesian NGOs. Cardno. <u>https://</u> <u>www.ksi-indonesia.org/assets/uploads/</u> <u>original/2020/02/ksi-1580493181.pdf</u> DeRue, D.S. and Ashford, S.J. (2010). Who will lead and who will follow? A social process of leadership identity construction in organizations. *Academy of Management Review*, 35(4), 627-647.

Dibley, T. (2019). Democratization and disability activism in Indonesia. In T. Dibley and M. Ford (Eds.), Activists in transition: Progressive politics in democratic Indonesia, (pp. 171-186). Cornell University Press.

Dibley, T. and Tsaputra, A. (2019). Changing laws, changing attitudes: The place of people with disability in Indonesia. In G. Fealy and R. Ricci (Eds.), *Contentious belonging: The place of minorities in Indonesia*, (pp. 77-94). ISEAS Publishing.

Dirth, T.P. and Nario-Redmond, M. (2019). Disability advocacy for a new era: Leveraging social psychology and a sociopolitical approach to change. In D.S. Dunn (Ed.), *Understanding the experience of disability: Perspectives from social and rehabilitation psychology*, (pp. 347-365). Oxford University Press.

Disability Rights Fund (n.d.) What is an "OPD"? <u>https://disabilityrightsfund.org/faq/what-is-a-dpo/</u>

Epitropaki, O., Kark, R., Mainemelis, C., and Lord, R.G. (2017). Leadership and followership identity processes: A multilevel review. *The Leadership Quarterly*, 28(1), 104–129.

DeRue, D.S. & Ashford, S.J. (2010). Who will lead and who will follow? A social process of leadership identity construction in organizations. *Academy of Management Review*, 35(4), 627-647. Foster-Fishman, P., Jimenez, T., Valenti, M. and Kelley, T. (2007). Building the next generation of leaders in the disabilities movement. *Disability and Society*, 22(4), 341-356.

Gardner, W., Avolio, B.J., Luthans, F., May, D.R., and Walumbwa, F. (2005). "Can you see the real me?" A self-based model of authentic leader and follower development. *The Leadership Quarterly*, 16(3), 343-373.

George, B., Sims, P., McLean, A.N., and Mayer, D. (2007). Discovering your authentic leadership. *Harvard Business Review*, 85(2), 129-138.

Gibney, J., Clarke, H., Kubenz, V., and Munro, E. (Eds.) (2021). Disability and leadership: New challenges - new possibilities. The Work Inclusivity Research Centre, The National Association of Disabled Staff Networks and PurpleSpace. <u>https://www.birmingham.ac.uk/</u> <u>documents/college-social-sciences/business/</u> <u>research/leadership-place/final-summary-</u> <u>report-august-2021.pdf</u>

Guterres, A. (2022, February 16). Advancing the rights of persons with disabilities around the world. Action 2030 Blog. <u>https://unsdg.un.org/</u> <u>latest/blog/secretary-general-remarks-</u> <u>global-disability-summit</u>

Hardy, D.M. (2021). Overcoming barriers to ascending to leadership roles for people with disabilities. PhD thesis, Walden University.

Harpur, P. and Szücs, B. (2022, February 22). Where are the leaders with a disability in higher education? *Times Higher Education*. <u>https://www.timeshighereducation.com/</u> <u>campus/where-are-leaders-disability-highereducation</u> Holden, D.L. and Basjir, W. (2016). *Peduli* program snapshot. The Asia Foundation. <u>https://www.dfat.gov.au/sites/default/files/</u> indonesia-peduli-program-snapshot.pdf

Hudson, D., Mcloughlin, C., Marquette, H., and Roche, C. (2018, February). Inside the black box of political will: 10 years of findings from the Developmental Leadership Program. Developmental Leadership Program. <u>https://www.dlprog.org/publications/</u> <u>research-papers/inside-the-black-box-ofpolitical-will-10-years-of-findings-from-thedevelopmental-leadership-program</u>

Imrie, R., 2004. Disability, embodiment and the meaning of the home. *Housing Studies*, 19(5), 745-764.

Irwanto, Kasim, E.R, Fransiska, A., Lusli, M. and Siradj, O. (2010). *The situation of people with disability in Indonesia: A desk review*. Centre for Disability Studies, University of Indonesia.

Irwanto and Thohari, S. (2017). Understanding CRPD Implementation in Indonesia. In L. C. Derrick and T.K. Reuter (Eds.), Making disability rights real in Southeast Asia: Implementing the UN convention on the rights of persons with disabilities in ASEAN, (pp. 95–118). Lexington Books.

Jackson, E., Craney, A., Motusaga, M., and Gibson, D. (2022, November). Supporting women's leadership in the COVID-19 response: Women leading and influencing in the Pacific. Developmental Leadership Program and Women Leading and Influencing. <u>https://</u> <u>dlprog.org/publications/research-briefs/</u> <u>supporting-womens-leadership-during-covid-</u> <u>19-women-leading-and-influencing-in-the-</u> <u>pacific/</u> Jones, A., Jones, C., and Ndaruhutse, S. (2014, March). *Higher education and developmental leadership: The case of Ghana* (Research Paper 26). Developmental Leadership Program. <u>https://www.dlprog.org/publications/</u> <u>research-papers/higher-education-and-</u> <u>developmental-leadership-the-case-of-ghana</u>

Kandasamy, N. and Soldatic, K. (2019). Kamalawathie: Gender, disability and leadership in Sri Lanka. In K. Soldatic and K. Johnson, (Eds.), *Global perspectives on disability activism and advocacy: Our way*, (pp. 97-113). Routledge.

King, J., Edwards, N. and Watling, H. (2021). Leadership for change: Pathways to activism for African women with disability. *Disability and Society*. Advance online publication. <u>https://doi.org/10.1080/09687599.2021.1994373</u>

Klandermans, B. (1997). The social psychology of protest. Blackwell.

Little, D.L. (2010). Identity, efficacy, and disability rights movement recruitment. *Disability Studies Quarterly*, 30(1), 1–17.

Liu, E. (2022). Because we are disabled, all the more reason to work! Exploring the voices and livelihoods choices of villagers with disabilities in Indonesia through collaborative participatory research. PhD thesis, Deakin University.

Luthans, F. and Avolio, B.J. (2003). Authentic leadership development. In K.S. Cameron, J.E. Dutton and R.E. Quinn (Eds.), *Positive organizational scholarship: Foundations of a new discipline*, (pp. 241-261). Barrett-Koehler.

Marchioro, C.A. (2000). The effect of leader disability on leadership perceptions. PhD thesis, The University of Akron. MacLeod, R. (2021). Core grants: The long and winding road to transformative funding. INTRAC and Laudes Foundation. <u>https://www.intrac.</u> <u>org/wpcms/wp-content/uploads/2021/06/</u> <u>core-grant-report-intrac-final-version.pdf</u>

Majiet, S. and Africa, A. (2015). Women with disabilities in leadership: The challenges of patriarchy. *Agenda*, 29(2), 101-111.

Menciptakan aktor difabel melalui sekolah gradiasi [Creating diffable actors through Gradiasi School]. (2019, November 12). Solider.id. <u>https://www.solider.id/baca/5596-</u> menciptakan-aktor-difabel-sekolah-gradiasi

Minas, H. and Diatri, H. (2008). Pasung: Physical restraint and confinement of the mentally ill in the community. *International Journal of Mental Health Systems*, 2, Article 8.

Murphy, S.E. and Johnson, S.K. (2011). The benefits of a long-lens approach to leader development: Understanding the seeds of leadership. *The Leadership Quarterly*, 22(3), 459–470.

Nario-Redmond, M.R. and Oleson, K.C. (2016). Disability group identification and disability-rights advocacy: Contingencies among emerging and other adults. *Emerging Adulthood*, 4(3), 207-218.

Nario-Redmond, M.R., Noel, J.G. and Fern, E. (2013) Redefining disability, re-imagining the self: Disability identification predicts selfesteem and strategic responses to stigma. *Self and Identity*, 12(5), 468-488.

Nazneen, S. (2019, October). *How do leaders collectively influence institutions?* (Foundational Paper 3). Developmental Leadership Program. <u>https://www.dlprog.org/</u> <u>publications/foundational-papers/how-do-</u> <u>leaders-collectively-change-institutions</u> Nursyamsi, F., Arifianti, E.D., Aziz, M.F., Bilqish, P., and Marutama, A. (2015). *Kerangka hukum disabilitas di Indonesia: Menuju Indonesia ramah disabilitas* [The legal framework on disability in Indonesia: Towards a disability-friendly Indonesia]. Pusat Studi Hukum dan Kebijakan.

Paglis, L.L. (2010). Leadership self-efficacy: Research findings and practical applications. *Journal of Management Development*, 29(9), 771-782.

Pendaftaran Sekolah Gradiasi tingkat dasar [Enrolment for foundation level Gradiasi School]. (2020, March 15). *Solider.id*. <u>https://</u> www.solider.id/baca/5773-pendaftaransekolah-gradiasi-tingkat-dasar

PNPM Special Program on Disability. (2015, June). Scoping and qualitative needs assessment of disabled persons organisations in Eastern Indonesia. [Unpublished report].

Priebe, J., and Howell, F. (2014). A guide to disability laws in Indonesia. The National Team for the Acceleration of Poverty Reduction. <u>https://www.tnp2k.go.id/downloads/a-guide-</u> to-disability-rights-laws

Priest, K.L. and Middleton, E. (2016). Exploring leader identity and development. *New Directions for Student Leadership*, 149, 37-47.

Procknow, G., Rocco, T.S. and Munn, S.L. (2017). (Dis)ableing notions of authentic leadership through the lens of critical disability theory. *Advances in Developing Human Resources*, 19(4), 362–377.

Putnam, M., Geenan, S., Powers, L., Saxton, M., Finney, S., and Dautel, P. (2003). Health and wellness: People with disabilities discuss barriers and facilitators to well-being. *Journal* of Rehabilitation, 69, 37–45. Putnam, M. (2005). Conceptualizing disability: Developing a framework for political disability identity. *Journal of Disability Policy Studies*, 16(3), 188–198.

Rodriguez, M.L. and Cohen, S. (1998). Social support. In H.S. Friedman (Ed.), *Encyclopedia of mental health*, Vol. 3, (pp. 535–544). Academic Press.

Rost, J.C. (1993). Leadership for the twentyfirst century. Praeger Press.

Salim, I. (2021). Keluar dari hegemoni pencacatan: Sebuah riset aksi partisipatoris pergerakan difabel Indonesia [Out of the hegemony of impairment: A participatory action research study of the Indonesian Disability Movement]. Penerbit PerDIK.

Samosh, D. (2021). The three-legged stool: Synthesizing and extending our understanding of the career advancement facilitators of persons with disabilities in leadership positions. *Business and Society*, 60(7), 1773–1810.

Schur, L.A. (1988). Disability and the psychology of political participation. *Journal* of Disability Policy Studies, 9(2), 4–31.

Schweisfurth, M., Davies, L., Symaco, L.P., Valiente, O., and Robles, C. (2016, September). Developmental leadership in the Philippines: Educational experiences, institutions and networks (Research Paper 39). Developmental Leadership Program. <u>https://www.dlprog.org/</u> publications/research-papers/developmentalleadership-in-the-philippines-educationalexperiences-institutions-and-networks

Scotch, R.K. (1988). Disability as the basis for a social movement: Advocacy and the politics of definition. *Journals of Social Issues*, 44(1), 159-72. Sebudubudu, D. (with Molutsi, P.)(2009, April). Leaders, elites and coalitions in the development of Botswana (Research Paper 2). Developmental Leadership Program. <u>https:// www.dlprog.org/publications/researchpapers/leaders-elites-and-coalitions-in-thedevelopment-of-botswana</u>

Sekolah Gradiasi dan harapan lahirnya aktivis difabel [Gradiasi School and hope for the birth of diffable activists](2020, September 15). *Solider. id*. <u>https://www.solider.id/baca/6272-sekolah-</u> <u>gradiasi-harapan-lahirnya-aktivis-difabel</u>

Shamir, B. and Eilam, G. (2005). What's your story? A life-stories approach to authentic leadership development. *The Leadership Quarterly*, 16(3), 395–417.

Shakespeare, T. (1993). Disabled people's self-organisation: A new social movement? *Disability, Handicap and Society*, 8(3), 249-264.

Smith, I., and Mueller, C.O. (2022). The importance of disability identity, selfadvocacy, and disability activism. *Inclusive Practices*, 1(2), 47–54.

Spark, C., Cox, J. and Corbett, J. (2018, February). *Being the first: Women leaders in the Pacific Islands*. Developmental Leadership Program. <u>https://www.dlprog.org/</u> <u>publications/research-papers/being-the-first-</u> <u>women-leaders-in-the-pacific-islands</u>

Sveningsson, S.F. and Alvesson, M. (2003). Managing managerial identities: Organizational fragmentation, discourse and identity struggle. *Human Relations*, 56, 1163-1193.

Uhl-Bien, M. (2006). Relational Leadership Theory: Exploring the social processes of leadership and organizing. *The Leadership Quarterly*, 17(6), 654–676. van Zomeren, M., Postmes, T., and Spears, R. (2008). Toward an integrative social identity model of collective action: A quantitative research synthesis of three socio-psychological perspectives. *Psychological Bulletin*, 134(4), 504–535.

Vergara, S. (2017). Lived history of a transformative leader with a disability: An evocative autoethnography for social justice. D.Ed thesis, Loyola Marymount University.

Watanabe, M. (2014). A phenomenological study of leadership: Developmental pathways of leaders with disabilities. D.Ed thesis, University of Montana.

Weeber, J.E. (2004). Disability community leaders' disability identity development: A journey of integration and expansion. PhD thesis, North Carolina State University.

# IMAGES (COURTESY OF THE RESEARCH TEAM)

- p.5 A female business owner shares her story of starting a chain of cafes employing deaf youth.
- p.11 Two deaf members of the research team interviewing a disability leader in person using remote live captioning.
- p.23 Members of the research team with staff from Puspadi Bali in front of the Annika Linden Centre in Denpasar.
- p.28 A member of the research team joined one of the founders of the Barrier Free Travel movement in Bandung to raise awareness of the importance of accessible public spaces.



The **Developmental Leadership Program** (DLP) is an international research collaboration supported by the Australian Government.

DLP investigates the crucial role that leaders, networks and coalitions play in achieving development outcomes.

dlprog.org dlp@contacts.bham.ac.uk @DLProg

Developmental Leadership Program International Development Department College of Social Sciences University of Birmingham Birmingham, B15 2TT United Kingdom

Design | squarebeasts.net



This publication has been funded by the Australian Government through the Department of Foreign Affairs and Trade. The views expressed in this publication are the authors' alone and are not necessarily the views of the Australian Government, the Developmental Leadership Program or partner organisations.







