



ADACAS

A D V O C A C Y

Response to **National Disability Strategy** **Position Paper** **(2nd round of consultations)**

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Contact:

Michael Bleasdale

CEO

manager@adacas.org.au

0447 423 185

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Unit 14 – 6 Gritten Street, Weston Community Hub, Weston Creek ACT 26111

PO Box 6137, Weston Creek ACT 2611

P: 61 02 6242 5060 | F: 61 02 6242 5063 | E: adacas@adacas.org.au | W: www.adacas.org.au

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1. About ADACAS

The ACT Disability Aged and Carer Advocacy Service (ADACAS) is a human-rights focussed organisation, which provides:

- Individual advocacy for and with people with disability, people experiencing mental ill health (or psychosocial disability), older people, and carers.
- Support to people making submissions to the Royal Commission into Aged Care Quality and Safety, and/or the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
- Assistance with National Disability Insurance Scheme (NDIS) related appeals to the Administrative Appeals Tribunal
- Redress Scheme support services to people who are survivors of institutional child sexual abuse
- Aged Care Navigator assistance to older people seeking assistance to understand the aged care systems
- Community Connection support and outreach to people with disability and carers from culturally and linguistically diverse (CALD) backgrounds.
- NDIS support coordination to a number of NDIS participants.

ADACAS additionally has a Policy and Projects team which engages in systemic advocacy, delivers projects to embed supported decision making approaches in service systems and explores practical responses to issues arising through individual advocacy and supported decision making. This team also prepares and delivers fee-for-service training on aged and disability related topics.

ADACAS staff work with individuals who are “falling through the cracks” in current service systems, and facing barriers to their rights being upheld, and to an experience of equitable access to services. ADACAS offers issues-based advocacy, and the topics of advocacy are multiple and varied, ranging from housing, to access to justice, to psychiatric treatment order hearings, to quality of service issues, to child protection processes, to restrictive practice/ restraint/ seclusion, to substitute decision-making, to aged care service issues, to NDIS and NDIS appeals etc.

ADACAS is a member of DANA, the Disabled Persons Advocacy Network, and OPAN, the Older Persons Advocacy Network.

ADACAS is based in Canberra and the ACT and has been providing free individual advocacy in this region for 28 years. ADACAS also provides free advocacy and information to people with disability in parts of NSW: specifically, in set areas of Shoalhaven, the Eurobodalla Hinterland, Batemans Bay, Broulee – Tomakin, Moruya – Tuross Head.

ADACAS acknowledges the language groups and Traditional Owners of the various lands on which we work: the Ngunnawal communities for our work in the Canberra area, the peoples from Dharawal and Yuin communities for our work on the NSW South Coast), and pay our respects to their Elders, and to all Aboriginal and Torres Strait Islanders in our communities.

2. Introduction

A strong National Disability Strategy (NDS) could play an important role in support of the changes needed to ensure that Australia fulfils its obligations to uphold the human rights of people with disability. These obligations include those outlined in the United Nations Convention on the Rights of Persons with Disabilities¹ and the many other international human rights treaties and conventions to which Australia is a party². Australia has additional broader obligations to all people, that are important to uphold, for example: Australia's commitment³ to the Sustainable Development Goals⁴. That the National Disability Strategy is currently being reviewed at the same time that a Royal Commissions into Violence, Abuse, Neglect and Exploitation of People with Disability, and a Royal Commissions into Aged Care Quality and Safety are both revealing horrifying truths about individual, organisation, policy, legislative and structural failures and the need for transformative change, is interesting timing. There is opportunity in taking account of the learnings to date from the Royal Commissions, but also the other learnings that have come from the experiences of people with disability through an unprecedented year of natural disasters in 2020 – bushfires, hailstorms, and now a pandemic.

For the NDS to function effectively – it is best developed as part of a partnership between government, with people with disability at the forefront (but also families/carers, advocacy/representative bodies and other stakeholders).

The NDS, the numbers and the role of the NDS:

There are approximately 4 million people with disability in Australia (18% of the population)⁵. Approximately 10% of these (400,000) are NDIS participants⁶. It is thus imperative that the new NDS focuses on all people with disability not solely the small percentage that will receive funding via the National Disability Insurance Scheme (NDIS).

The AIHW also report that the prevalence of disability increases with age, with “Around 1 in 8 (12%) people aged under 65 have some level of disability, rising to 1 in 2 (50%) for those aged 65 and over.”⁷ Given that to be eligible to apply for entry to the NDIS, you must be aged under 65, this means that most people with disability

¹ UN General Assembly (2007), *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): resolution / adopted by the General Assembly, 24 January 2007*, available via: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> and accessed in October 2020.

² Law Council of Australia (2020), *Australia's International Human Rights Obligations website*, available at: <https://www.lawcouncil.asn.au/policy-agenda/human-rights/australias-international-human-rights-obligations>, accessed in October 2020.

³ United Nations, (2018), *Voluntary Review of the Sustainable Development Goals*, available via: <https://sustainabledevelopment.un.org/memberstates/australia>, accessed in October 2020.

⁴ United Nations General Assembly (2015), *Transforming our world : the 2030 Agenda for Sustainable Development*, Sustainable Development Goals Excerpt: available via <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>, accessed in October 2020.

⁵ Australian Institute of Health and Welfare (2020), *People with disability in Australia 2020: in brief*. Available via: <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2020-in-brief/contents/how-many-people-have-disability>, accessed in October 2020.

⁶ National Disability Insurance Agency (2020), Article on NDIS website: “There are now 400,000 NDIS participants”(August 2020), Available via <https://www.ndis.gov.au/stories/5067-there-are-now-400000-ndis-participants>, accessed in October 2020.

⁷ Australian Institute of Health and Welfare (2020), *People with disability in Australia 2020: in brief*. Available via: <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2020-in-brief/contents/how-many-people-have-disability>, accessed in October 2020.

over 65 receive any disability support services via other systems (such as the Aged care and health systems). It also means that community-based and government initiatives, such as the “Age-Friendly City” plan in the ACT, need to take into account the disability-related requirements of older people, and thus need to be at least referenced in the NDS. The NDS must take heed of the fact that the prevalence of disability increases with age, and be a strategy that provides support and leadership for the changes needed in ensuring rights are upheld for and with all people with disability across the lifespan.

The NDS also needs to be inclusive – which means explicitly acknowledging diversity and intersectionality. A gender lens should be applied to consider the impact of gender in processes and outcomes. There should be consideration of the impacts of class, of cultural and linguistic diversity, of having had experiences of trauma and abuse, of impacts of socio-economic context. Given the changes over the last 10 years, it is important that the NDS explicitly acknowledges that disability arising from mental ill health fits in scope (alongside other types of disability). There also needs to be consideration of the needs of regional/rural and remote communities where people with disability might be living.

3. Vision and Outcome Areas:

Question 1: During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

Whilst we support the outcome areas, we would suggest that two of them be renamed to ensure all aspects are adequately captured, specifically -

1. Economic Security should become “Economic Security, Employment and Housing”
5. Learning and Skills should become “Education, Learning and Skills”

We make these suggestions in light of the importance of a strong (increased) focus and outcomes in each of these additional topics: especially in relation to Housing. Whilst we are advocating for Housing to be specifically named against a particular outcome area, we also recognise that access to safe, suitable and accessible housing has the potential to positively impact outcomes across most if not all of the outcome areas.

4. Guiding Principles

Question 2: What do you think about the guiding principles proposed here?

The paper lists guiding principles in addition to those set out in Article 3 of the UN CRPD.

We consider that the principles set out in Article 3 of the UNCRPD should be explicitly included amongst the Guiding principles.

In relation to some of the other suggested principles, our comments:

- **Involve and engage:** whilst involving and engaging with people with disability is clearly important, in our view it is not enough - there needs to be a clear shift towards co-design and co-production – the sharing of power with people with disability and their families/carers and representative/advocacy organisations.

- Design universally: we agree in principle – but would like the wording in relation to this principle to reflect a commitment to ensuring that processes are accessible, and assistive technology is used. Given the existing body of literature about “universal design”, we would suggest the principle include the words “universal design” rather than be framed “design universally”.
- Engage the broader community: the wording needs to be refined and clarified – what is meant by engage? Are the community being asked to act? Is this in relation to awareness-raising, working with and educating? How does this relate to the community attitudinal change that is proposed (see our response to question 3 over the page).
- Address barriers faced by priority populations/: please define - what priority populations are being referred to? How is it being decided which populations are priority populations?
- Support carers and supporters: this is an important guiding principle.

We would suggest additional principles:

- Decision-making and leadership by people with disability
- Uphold human rights
- Ensure that there is a disability-inclusive research-base and that approaches are evidence-informed
- Responds flexibly to the diversity of people with disability: the strategy should be a strategy for all people with disability and take account of/respond to the full dimensions of diversity, and also the breadth of experiences and systemic issues affecting people with disability such as access, the right to housing, income security and paid employment.

5. Community Attitudes

Question 3: What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Australia's awareness-raising obligations (Article 8)⁸ require Australia to combat stereotypes against and highlight strengths (capabilities)⁹ of persons with disabilities. These are in effect obligations to act to improve community attitudes. Given these obligations, and the negative impacts that stereotypes and misinformation about disability and rights can have: in our view it would be useful for the National Disability Strategy include a section on improving community attitudes.

Whilst recognising the importance that community attitudes change, it is imperative that any efforts to change community attitudes are well-thought out, research-based, effective and lead by people with disabilities and carers.

The approach towards and funding of changing community attitudes also need to be proportionate, manage known risks¹⁰ and avoid a situation where too strong a focus (and too much funding towards) improving community attitudes occurs at the expense of the many other substantial outcomes being sought by people with disability.

6. Strengthening Accountability

Question 4: How do you think clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

Whilst outlining which government is responsible for which actions is important, naming who has responsibility to date has not proved sufficient to address the issues that are too often arising between siloed entities, or when two governments, or two areas of government are (or should be) mutually responsible for improved outcomes as they affect individual people with disability. At present there are many examples of situations where the person with disability's rights and needs are not put first, where different governments or different departments within governments argue with each other, or try to avoid responsibility or move responsibility to the other party, all the time not providing support to the person with disability despite their right to such support/s.

We provide a few examples:

- **Interface issues between the NDIS and other sectors:** ADACAS Advocates assist people who are appealing NDIS decisions. Some of the appellants are people with disability are seeking entry (or re-entry) to the scheme, others are

⁸ UN General Assembly (2007), Article 8 of the United Nations *Convention on the Rights of Persons with Disabilities (UNCRPD): resolution / adopted by the General Assembly, 24 January 2007*, available via: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-8-awareness-raising.html> and accessed in October 2020.

⁹ UN General Assembly (2007), Article 8 of the United Nations *Convention on the Rights of Persons with Disabilities (UNCRPD): resolution / adopted by the General Assembly, 24 January 2007*, available via: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-8-awareness-raising.html> and accessed in October 2020.

¹⁰ Christiano, Ann and Neimand, Annie (2017), "Stop Raising Awareness Already", an article in the Stanford Social Innovation Review, available online at: https://ssir.org/articles/entry/stop_raising_awareness_already and accessed in October 2020.

current NDIS participants seeking a suitable level of supports. We see daily the issues that arise when there is a need for support in a situation where there is a dispute between governments as to who should respond. Disputes frequently arise between the NDIA and the Health systems about who is responsible to fund specific supports. In the meantime, instead of the support being provided, and the governments resolving the dispute in the background, at present, the person usually is put in the middle of the issue, sent back and forth between systems and frequently subjected to long delays during which period they do not have vitally needed supports.

- Interface issues between the Commonwealth and State Governments affecting people receiving aged care services, especially people living in residential aged care. The Commonwealth government funds the aged care system and services. State/territory governments fund healthcare services. The rate of mental ill health for older people living in residential aged care is much higher than that of older people living in the community. Despite this, aged care residents who experience mental ill health (many of whom also have a co-occurring disability) do not currently have equitable access to mental health supports. In our view, a (false) distinction is drawn between “welfare” supports, and “mental health” supports, with both governments not adequately funding or ensuring sufficient access to either of these integral and inter-related supports.

It is imperative that there be regular high-level cross-departmental and whole-of-government approaches to addressing shared responsibilities.

ADACAS feedback re Strengthening Accountability

In looking at how accountability can be strengthened, we recommend:

- That co-design and co-production between government with people with disability, their families/carers, representative and advocacy organisations and other key stakeholders be coordinated and required at all levels (not solely at national levels, but also at local and state levels), and especially in the development of targeted action and engagement plans.
- That accountability is focussed on accountability to all people with disability and their families/carers, not solely the 10% of people who are NDIS participants.
- Ensuring that efforts to achieve change are informed by robust academic research and science, and the evidence-base around how change is achieved.
- That there is Independent reporting against outcomes (perhaps by the Productivity Commission, in conjunction with disabled persons representative and advocacy organisations) and independent monitoring of efforts to ensure co-design/co-production processes.
- Increased funding for disabled people's organisations, disability representative organisations and especially for individual advocacy to work with people with disability, people with mental ill health of all ages, in recognition that systemic and independent advocacy provide a vital safeguarding role to assist people in having rights upheld.
- That, as suggested during the National Disability Strategy September 2020 forum hosted by the Human Rights Commission:
 - that there is a robust data, research and evidence plan, to help as part of a framework for accountability.
 - That there is a strong cross-portfolio approach within government to ensuring that there is the necessary leverage and commitment to achieve the necessary change.
- Invest in better training disability support workforces (whether these are community funded, funded through disability or aged care or other systems), so that they are better able to support good practice/outcomes.
- That there is a much more nuanced and deliberate effort to specifically address siloing, and interface issues between government departments and between governments. We highlight housing as an example of a topic where specific targeted practical action is needed, and one where siloing (and not working together cross-departmentally for solutions) can have a particularly damaging impact.
- That reporting on progress to achieving outcomes be public, transparent, regular, and meaningful. It should include evidence and explanation as to any progress being made. National data should be reported publicly to Parliament, and made available online, and in addition to the National deadlines, there should be transparent public reporting at the local level on progress towards the jurisdictional related changes to achieve the needed ends.
- Monitoring and evaluation should be outcome based, and ongoing, and fed directly back into those driving initiatives to achieve change, such that adjustments can occur as more is learnt along the way.

ADACAS endorses the comments by ACTCOSS, in their submission to the Senate Standing Committees on Community Affairs in 2017 about accountability and the National Disability Strategy:

“Noting that the Strategy is a whole of government and whole of community strategy, we would support consideration being given to innovative, tailored

and fit for purpose methods of tracking progress under the Strategy including the option of using deliberative methodologies such as a Citizen's Jury.

People with disability also experience dual disadvantage and multiple vulnerabilities, especially to violence. Aboriginal and/or Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds and people who identify as LGBTI who also have a disability also have poor outcomes in a range of life areas.

We support linking NDS to other frameworks, such as the National Plan to Reduce Violence against Women and their Children, Closing the Gap and the National Framework for Protecting Australia's Children. There should also be links to frameworks which address the needs of people in dual disadvantage."¹¹

ADACAS recommends that people with disability are paid for their time and the lived experience expertise that they bring to any accountability mechanisms such as co-design/co-production efforts, and Citizen's jury. We also observe that systemic advocacy/disability representative organisations (such as, here in the ACT, Women with Disabilities ACT (WWDACT)), if funded appropriately, can provide robust insights into the experiences and concerns of people with disability, and that this can be a path to add additional insight.

Question 5: How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability? (Examples of the non-government sector include big, medium and small businesses, community organisations, employees of these businesses, private research, investment organisations and individuals.)

After people with disability, and their families/carers, non-government organisations, especially those which focus on amplifying the voices of people with disability (including disabled persons organisations, disability and carer representative/advocacy organisations), should be the next partners with government on achieving the strategic aims being set. Many non-government organisations are a vital part of the disability support infrastructure, and can be positioned well to lead, contribute towards and participate in change. Along with people with disability and family/carers, disabled persons organisations, disability representative organisations and advocacy organisations are especially well-placed to provide alerts around what needs to be improved/ what is not working and contribute towards solutions. We encourage greater levels of funding towards these organisations accordingly.

It is important also to recognise that the non-government sector is not one single homogenous group. Any representation of this sector (and planning for its multiplicity of roles) must occur in a nuanced way, and adequately and accurately reflect and take account of the diversity of sector. The values and practices of organisations can vary widely, as can organisational size, focus and scope. There can be massive differences between the role of for example, some of the large multinational not for profits as compared with some of the small locally based medium-sized private businesses, when compared again with advocacy and human rights organisations.

¹¹ ACT Council of Social Service (ACTCOSS) (2017), *Submission – Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities*, available via: <https://www.actcoss.org.au/sites/default/files/public/publications/2017-submission-delivery-of-outcomes-under-national-disability-strategy-2010-20.pdf>, accessed in October 2020.

For the NDIS, the NDIA continues to have a huge influence on orienting direct service delivery organisations towards more business-focussed practices (away from more flexible models which ironically, in some situations had in the past been able to offer more choice and control for people with disability). There is value in the diversity of the sector: in further developing the National Disability Strategy, we encourage government to recognise and work with the non-government sector in its diversity to seek to exceed desired outcomes.

We note also and support efforts in the ACT to improve the power balance, dynamics and approach between government and non-government organisations, by further developing and strengthening partnerships in efforts to look at commissioning as a strategy for social impact¹². Given the need for greater co-design and co-production as the National Disability Strategy is developed, we encourage similar considerations to occur on how partnerships might be improved and power better shared with people with disability, carers, and also the relevant elements of the non-government sector.

Question 6: What kind of information on the Strategy’s progress should governments make available to the public and how often should this information be made available?

This is another topic where co-design/co-production is vitally important. Government must be partnering and sharing power with people with disability, families/carers, disability representative and advocacy organisations and other key stakeholders in a process to determine how progress should best be measured in the different domains.

In our view Government should afford a higher priority to the status of the NDS and its commitment to meeting its obligations as a signatory to the Optional Protocol of the CRPD, and make comprehensive information available to the public on the Strategy’s progress. Ideally the Prime Minister should be reporting to Parliament on progress towards outcomes annually. Progress should be measured in a diverse range of ways, and should include both quantitative and qualitative approaches.

There needs to be a balance struck to ensure that reporting happens frequently enough to ensure that progress is on track, and for accountability purposes (and to allow for adjustments to occur in response to the reports as needed), but also at the same time, not so frequently that too much time is taken away from the achieving the outcomes sought under the strategy. We note that there were concerns about the timeliness of the bi-annual reporting highlighted in relation to the last National Disability Strategy¹³, and that timeliness of reporting is crucial. We believe there should be consideration of staggering some of the reporting timelines and that timelines should match local jurisdictional opportunities for change.

¹² ACT Government (2019), Strengthening Partnerships: Commissioning for Social Impact website and submissions, available via: https://www.communityservices.act.gov.au/about_us/strategic_policy/strengthening-partnerships-commissioning-for-social-impact/strengthening-partnerships-discussion-paper-no-1, accessed in October 2020.

¹³ ACT Council of Social Service (ACTCOSS) (2017), *Submission – Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities*, available via: <https://www.actcoss.org.au/sites/default/files/public/publications/2017-submission-delivery-of-outcomes-under-national-disability-strategy-2010-20.pdf>, accessed in October 2020.

In terms of what should be measured/considered ADACAS believes there should be a set of robust but meaningful indicators established, which includes both lead and lag indicators. In addition, there should be indicators in relation to over-representation of people with disability experiencing negative life events, e.g. a reduction in numbers of people with disability becoming homeless, reductions in numbers of people with disability being incarcerated, reduction in numbers of people with disability experiencing inequitable experiences of the health system etc.

There should also however be measures that are examining the data on strengths-based outcomes, evidence being measured that people with disability are having their rights upheld and opportunities made equitably available to them For example that there is a marked increased numbers of people with disability (anonymously) reporting that their workplace is both supportive and inclusive, a marked increase in the numbers of people with disability reporting good access to educational opportunities, etc.

Indicators should also be relevant to diverse types of approaches, for example we would expect that the NDS should encourage additional legislative reform that upholds the rights of people with disability, i.e. legislation that:

- strengthens human rights protections, and ensures much greater efficacy of the disability discrimination act (and the mechanisms by which it is ensured that compliance occurs), such that the responsibility does not continue to fall primarily onto people with disability to themselves pursue discrimination complaints, and/or litigation personally in order to seek to require change to occur.
- embeds additional universal design principles across relevant legislation (in fields as diverse as housing (national construction code), education, justice etc).

Any reporting of the NDS needs to be able to measure progress towards this occurring. It would be acceptable for there to be an overarching schedule of reporting, but also schedule of reporting that is tailored to jurisdictions. We also support calls from organisations such as ACTCOSS for there to be innovative mechanisms to assess impact of the strategy, including ideas such as citizen juries, with broad and diverse representation (see page 9 of this report for more information on this suggestion).

7. Targeted Action Plans

Question 7: What do you think of the proposal to have Targeted Action plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years?)

We agree that targeted action plans that focus on making improvements in specific areas within a defined period of time, if resourced appropriately, can be a mechanism to generate change. We observe that the success of any such action plans will depend both on the quality of the process by which they are developed, and the quality of the final plans, and that adequate resourcing is made available.

We recommend that they be developed via robust co-design processes in partnership with people with disability and their families/carers, representative and advocacy bodies and other stakeholders. We note that we would expect that there would need to be a variety of plans as different opportunities/timings/actions will be relevant in different areas of Australia/settings (i.e. rural/regional areas vs

metropolitan etc). We suggest there should also be mechanisms to hold to account and address issues that might be preventing outcomes being achieved.

8. Engagement Plan

Question 8: How could the proposed Engagement Plan ensure people with disability and the disability community, are involved in the delivery and monitoring of the next Strategy?

We appreciate that government wishes to make a commitment to ensuring that people with disability can actively participate in shaping future disability policies, programs and services. We would advocate for this plan to be strengthened into a co-design/co-production approach. The current wording: which includes a “commitment to actively participate”, and a name “engagement plan” do not indicate suggest any sharing of power by government with others. We recommend revising wording to embed a commitment to co-design, co-production and leadership from people with disability.

As earlier mentioned, we recommend that people with disability/carers participating in the delivery and monitoring of the strategy are paid for their time and lived experience expertise.

9. Conclusion:

At present, Australia continues to fail many people with disability.¹⁴ The trauma, abuse, violence, neglect, exploitation and discrimination that people with disability are experiencing in so many scenarios and across the lifespan is unacceptable.

People with disability deserve to have their human rights upheld, consistently and in an ongoing way. People with disability deserve to have equitable access to services and structures, to employment, to education, to housing, to family life etc.

The Royal Commissions, and the new National Disability Strategy (beyond 2020): have the potential to achieve profoundly positive impacts for people with disability, their family/friends/carers, over the next 10 years.

The time for transformative change is here.

¹⁴ Australian Disabled People’s Organisations (DPOs), Disability Representative Organisations (DROs) and Disability Advocacy Organisations (2019), *Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities UN CRPD Review 2019*, available online via: <https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf>, accessed in October 2020.