



Scoping review of position papers that aim to enhance the lives of people with intellectual disability

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Executive summary

This scoping review identifies 125 position papers that aim to enhance the lives of people with intellectual disability in the Australian and Aotearoa New Zealand regions, or further afield. A framework analysis of the documents reveals 35 topics across six key themes, with a gap analysis identifying a further seven topics for which no position papers could be found (42 topics altogether). An annotated bibliography is provided to aid further analysis, and to inform future direction for the Australian Society for Intellectual Disability's (ASID) systemic advocacy. This scoping review also briefly defines and discusses the notion of 'position paper', a term that is often confused with similar terminology (position statement, discussion paper etc), and produces a set of recommendations for how ASID may wish to work collaboratively with partners and members to catalyse the development of further position papers.

Introduction

In July 2019 the Australian Society for Intellectual Disability commissioned a scoping review to examine the breadth and nature of current evidence-based position papers that aim to enhance the lives of people with intellectual disabilities living in Aotearoa New Zealand and Australia. Edith Cowan University (ECU) was commissioned to conduct the scoping review. A total of 125 position papers were gathered and collated into a matrix (see Appendix 1), and analysed using framework analysis. In the process, the researchers mapped out a list of position paper topics, organised into six central themes:

1. Lifespan Development
2. Community Living
3. Individual Autonomy
4. Health and Wellbeing
5. Rights and Advocacy
6. Service Approaches

This report provides an overview of the process of data collection and analysis, and presents findings and recommendations for how ASID may wish to proceed. The report also briefly defines and discusses the difference between position papers, position statements, policy directives and other similar types of documents, and the usefulness of position papers in translating research into policy and practice.

About the Authors

Adam Johnson is currently finalising a PhD project which analysed social policy and practice in relation to disability access and inclusion in a local government area and [produced a report and recommendations for the City of Bunbury](#). He teaches a unit on social inclusion and intellectual disability at ECU. He is also the current chair and past CEO of Advocacy WA, a non-government disability and mental health advocacy organisation based in the South West region of WA. Adam's prior professional experience includes positions with the Disability Services Commission (as a Local Area Coordinator), NGO disability providers (as a Service Coordinator) and local government (as a Community Development Officer). Adam has a keen interest in the impact of policy on the everyday lives of people with intellectual and other disabilities, and is committed to researching best practice. He is personally connected with many people with intellectual disabilities, some of whom participated as co-researchers in his PhD project.

Kathy Boxall is Professor of Social Work and Disability Studies at ECU's South West Campus in Bunbury. Kathy is a qualified and experienced social worker who has worked with people with intellectual disabilities and their families from a range of cultural backgrounds. She also has many years' experience undertaking research in the areas of intellectual disability and mental health. She has a particular interest in researching service user perspectives, having been on the receiving end of mental health services herself many years ago. Kathy is a skilled social researcher with experience of conducting national (UK) surveys, service user consultations, small scale qualitative studies and collaborative projects with local government, NGOs and service user organisations, and has published extensively in these areas (<https://scholar.google.com/citations?user=DnN8SdUAAAAJ&hl=en>) as well as preparing reports for government and industry. Kathy has also been involved in supporting self-advocacy groups and individuals in relation to complaints to service providers and Ombudsman appeals. She was a member of the Management Board for CHANGE (a UK-based organisation which campaigns for the rights of people with intellectual disabilities - <https://www.changepeople.org/#AboutUs>) and has a good understanding of the interfaces between research, policy and practice. She has presented regularly at international seminars and conferences over many years and has an extensive network of contacts in the intellectual disability field.

Defining Position Papers

In conducting this scoping review, we were struck by the lack of consistency in how position papers are presented to their audiences. There did not appear to be a shared understanding of position papers or position statements. It was also difficult to find guidelines or definitions to assist organisations seeking to prepare such documents. This section briefly defines and discusses differences between position papers and position statements, and their role in translating research into policy and practice.

Position papers or position statements?

According to Goffin & Myers (1991) there is no common definition of what is meant by either position statement or position paper and position statements and position papers are often confused with each other.

A position statement can be considered a concise statement of an organisation's official position on a critical issue, and is usually between one to several sentences in length (CDHA, n.d.). A position paper is lengthier: it contains a comprehensive review and critical analysis of specific issues, and also includes recommendations (Reiner, 2013). Thus, a position statement is usually developed based on the findings of a position paper (CDHA, n.d.), which is itself explicitly evidence-based (Goffin & Myers, 1991) and provides a philosophical foundation for reform (Duhaney, 1999).

Position papers can build on new research or emerging values, as well as industry discussion papers or expert consensus, and can be used to develop position statements and inform policy and practice guidelines. In this way, position papers play an important role in translating research into practice, as shown in the Figure 1 opposite:

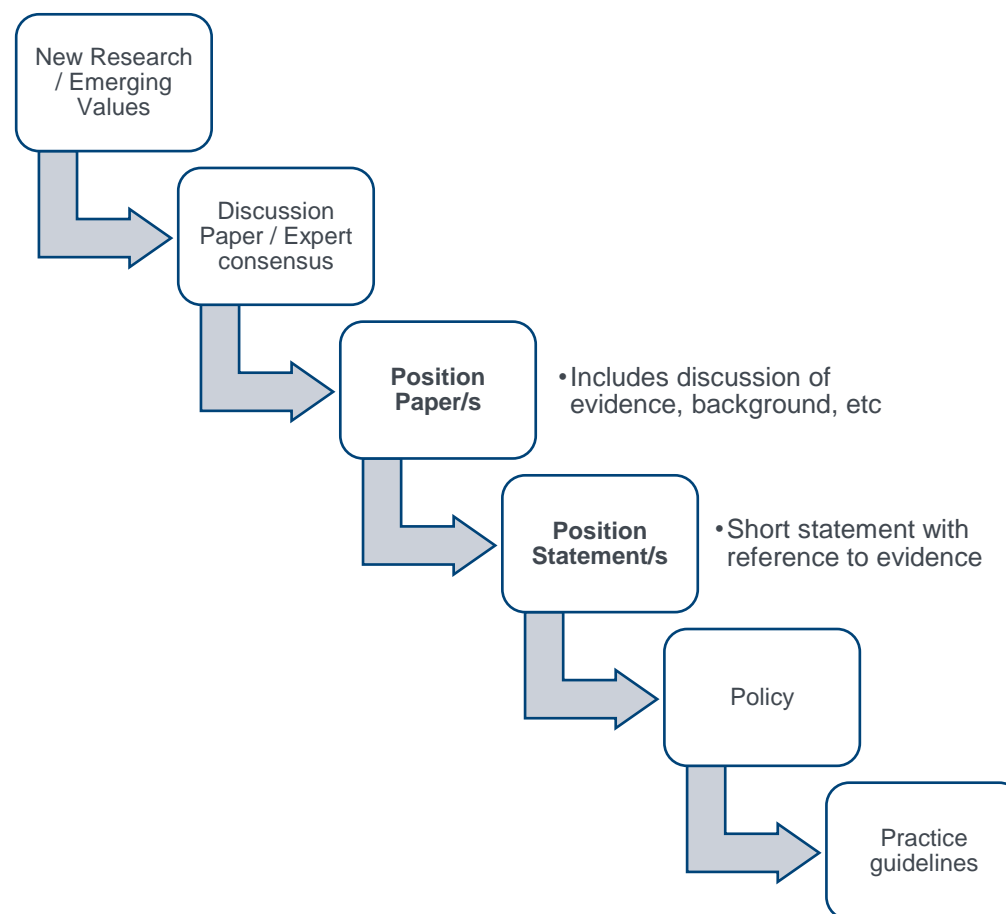


Figure 1: the role of position papers in translating research into policy and practice

Who develops position papers and why?

Position papers are developed by a range of organisations, but most often by peak bodies advocating a particular position on behalf of their members (Reiner, 2012). They are usually intended to influence government policy, but may also be used to shape the practices of member organisations and bring about cultural change. Some position papers are intended to eliminate undesirable practices (such as restrictive practices¹), or to promote positive practices (such as inclusive education²). Position papers can be used to support an organisation's leadership (Luckasson et al, 2017), equip consumer and advocacy groups (Luckasson et al, 2017; Mooney, 2004) and inform submissions on issues of public policy (Luckasson et al, 2017). It is worth noting however that very few position papers are developed by consumer groups (Borry et al, 2006), which is reflected in the current scoping review.

Most organisations only develop a handful of position papers. Of the 45 organisations identified within the current scoping review, only ten organisations had three or more position papers related to intellectual disability (The Arc / American Association on Intellectual and Developmental Disabilities [AAIDD]) – 38 combined; Inclusion International – 7; the Office of the Public Advocate Victoria – 7; NSW Council for Intellectual Disability – 6; Women With Disabilities Australia – 5; Division for Early Childhood of the Council of Exceptional Children – 4; Australasian Society for Intellectual Disability – 3; the Royal Australian and New Zealand College of Psychiatrists – 3; and the Social Care Institute for Excellence – 3).

What are the hallmarks of quality position papers?

High quality position papers share some common features, they:

- a) Make their principles explicit (CDHA, n.d.)
- b) Are values-driven, and not neutral in their stance (Goffin & Myers, 1991)
- c) Are clear in their motivations and context (Duhaney, 1999)
- d) Provide definitions of key terms rather than assuming a shared understanding (Hawryluck, 2006)
- e) Present a clear position with supporting evidence (Xavier University, 2014)
- f) Discuss both sides of the issue (Xavier University, 2014)
- g) Outline suggested courses of action and possible solutions for consideration (Xavier University, 2014)

How are position papers disseminated?

Position papers are typically published on the organisation's website (Luckasson et al, 2017), and emailed to members. Some are published in industry journals. Often, a copy is sent to politicians, policy makers, government bureaucrats and/or the media, and may be communicated through briefings, social media, published media and email networks (CDHA, n.d.). It has been argued that position papers and position statements sometimes lack impact due to inadequate theoretical development or poor implementation (Duhaney, 1999). Some organisations may not use technology effectively to aid translation of position papers and statements into policy (Reiner, 2012). Goffin & Myers (1991) suggested that position statements rely on the power of persuasion, which requires intensified efforts to actualise proposed solutions in practice and policy. The literature around 'knowledge exchange' (Reed et al, 2008) describes knowledge as a process (rather than a 'thing'), and specifically a social

¹ [PP 011] Australasian Society for Intellectual Disability. (2010). *Official Position Statement Against the Use of Restrictive Practices in the Support of People who Have an Intellectual Disability*. Retrieved from https://www.asid.asn.au/files/708_2010_may_restrictive_practices.pdf

² [PP 002] Down Syndrome Australia. (2017). *Position Paper on Education*. Retrieved from <https://www.downsyndrome.org.au/>

process. Thus, cultivating direct relationships with key decision-makers and timing the release of position papers and position statements to coincide with the policy cycle is critical to successful translation (Reed et al, 2014). A key issue appears to be the difficulty in locating position papers on particular issues, as they are often buried within various organisational websites under obscure links.

There does not appear to be any central repository for position papers relating to intellectual disability anywhere in the world.

Search Strategy and Data Collection

Because most position papers are published on organisational websites, the primary search engine used to locate position papers was Google Search. We also used Google Scholar other research databases, and searched industry journals.

Position papers were included in the scoping review if they were clearly identified as position papers or articulated a particular position, and if they primarily discussed people with intellectual disability, or included people with intellectual disability as a major target group. Documents primarily about autism, physical, sensory and psychosocial disabilities were excluded from the search.

Those documents described as position papers but which were more akin to guidelines, procedures, fact sheets or internal policy documents were excluded. Documents that lacked an explicit or credible evidence base were also excluded; however, position papers produced by people with intellectual disability and endorsed by an organisation as a position paper were included (for example, position papers produced by Inclusion Australia^{3 4}).

Position papers published between 2009-2019 were preferenced, but some papers published in earlier periods were included if they presented a perspective not articulated by other more recent position papers.

Position papers from within Australia and New Zealand were preferenced, but international papers were included if they met the criteria above. Only papers presented in English were included.

Primary search terms related to disability included combinations of *intellectual, cognitive, learning, disability, difficulties* and *impairment*. Primary search terms related to position papers included combinations of *position, paper, policy, and statement*.

Where a position paper was located on an organisation's website, the website was searched for the existence of more papers.

Organisations were also searched by name. Many notable organisation websites such as British Institute of Learning Disabilities, Norah Fry, Donald Beasley Institute, and the Independent Living Institute (Roeher Institute) were found to contain many useful resources and research papers, but did not appear to contain any position papers.

Topical search terms were compiled based on the authors' industry knowledge (see *About the Authors* section above) derived from our experience in research and advocacy, including recent research with a group of people with intellectual disability about the everyday impact of Australian social policy (Boxall et al., 2018). The list of topical search terms was expanded as the research progressed, resulting in 42 focus topics, which are expanded in the sections below and presented in their entirety in Appendix 1. The position papers addressed 35 topics, leaving 7 topics for which position papers could not be found ('gaps').

A total of 125 position papers were identified from 45 organisations, of which 30 were from Australia and/or Aotearoa New Zealand, and 15 from other countries.

³ [PP 109] Inclusion Australia. (n.d.). Bullying and diversity through language: a new way of thinking about this issue. Retrieved from <https://www.inclusionaustralia.org.au/about-us/our-voice/>

⁴ [PP 116] Inclusion International. (2008). Position Paper - "A Right to Life". Retrieved from https://inclusion-international.org/wp-content/uploads/2013/07/Position_Paper-A_Right_to_Life1.pdf

The following table lists the 45 organisations that have published position papers. The number of position papers produced by each organisation that met the scoping review search criteria is indicated on the left. The table is ordered by this number, so that the most prolific organisations are listed first.

30	The Arc
8	American Association of Intellectual & Developmental Disabilities (AAIDD)
7	Inclusion International
7	Office of the Public Advocate (Victoria)
6	NSW Council for Intellectual Disability
5	Women With Disabilities Australia (WWDA)
4	Division for Early Childhood of the Council of Exceptional Children
3	Australasian Society for Intellectual Disability (ASID)
3	Royal Australian and New Zealand College of Psychiatrists
3	Social Care Institute for Excellence (SCIE)
2	Agency for Clinical Innovation (NSW)
2	Australian Association of Developmental Disability Medicine
2	Australian Human Rights Commission
2	Disabled People's Organisations Australia
2	Down Syndrome Australia
2	Early Childhood Intervention Australia (ECIA) NSW/ACT
2	Family Advocacy
2	Inclusion Australia
2	International Association for the Scientific Study of Intellectual Disabilities (IASSID)
2	La Trobe University Living With Disability Research Centre
2	Office of the Public Advocate (Queensland)
2	Royal Australasian College of Physicians
2	VALID - Victorian Advocacy League for Individuals with Disability

2	Validity
1	Academy of Dentistry for Persons with Disabilities
1	AMA - Australian Medical Association
1	Annual Round Table on Intellectual Disability Policy in Victoria
1	Australian Association of Social Workers (AASW)
1	Better Health (Government of Victoria)
1	British Psychological Society, Division of Clinical Psychology Faculty for People with Intellectual Disabilities
1	Canadian Paediatric Society
1	Dimensions UK
1	Family Planning NSW
1	National Joint Committee for the Communication Needs of Persons with Severe Disabilities
1	NDS
1	NDS (NSW)
1	NSW Council of Social Service: Disability Network Forum
1	Professional Association of Nurses in Developmental Disability Australia
1	Queensland Advocacy Inc.
1	Royal Far West
1	RTI Action Network
1	Society of Paediatric Nurses
1	Stand By Me
1	Texas Council for Developmental Disabilities
1	UNSW

Data Analysis

Each position paper was assigned to one of 42 topics, which were in turn ordered into six themes.

Theme 1: Lifespan Development includes position papers that relate to life stages, including early childhood through to death, and includes school years and education, transition from school to adulthood, parenting and aged care.

Theme 2: Community Living includes position papers that relate to living in the community as an adult with ID, including accommodation, employment, volunteering, income support, transport, leisure and social inclusion.

Theme 3: Individual Autonomy includes position papers that relate to personal autonomy including decision-making, self-determination, and citizenship, as well as making friends, setting goals, accessing information and developing leadership potential.

Theme 4: Health and Wellbeing includes position papers that discuss health related issues such as diagnosis, health care, hospitalisation, dental and medication management, as well as sexuality and reproductive health, mental health and wellbeing and spirituality.

Theme 5: Rights and Advocacy includes position papers that discuss the connection between disability rights and quality of life, discrimination, safeguarding and advocacy, how the law deals with people with intellectual disabilities, guardianship, and conducting research related to intellectual disability.

Theme 6: Service Development: includes position papers that focus on service approaches such as service planning and coordination, consultation and feedback, restrictive practices, dedifferentiation, staff training, management of funding, and service improvement.

Gaps in the existing collective of position papers have also been identified. It should be noted that gaps in position papers do not equate to gaps in research, as research papers exist for most, if not all of the topics covered in this scoping review. However, it was outside the remit of this review to gather related research papers.

It should be noted that each position paper does not always sit neatly into one particular topic or theme, but often covers a number of different topics and themes in its pages. The authors assigned each paper to its most prominent topic.

Theme 1: Lifespan Development

#	TOPIC	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10
1.1	Gestation & birth	PP 3									
1.2	Early childhood education & intervention	PP 31	PP 49	PP 54	PP 56						
1.3	School years (incl mainstreaming)	PP 2	PP 32	PP 85	PP 104	PP 112					
1.4	Post-school years (incl transition to)	PP 69									
1.5	Parenting (with ID)	PP 7	PP 39	PP 121							
1.6	Aging & aged care	PP 29	PP 72	PP 122							
1.7	Death, wills & funeral	PP 24									PP = Position Papers

A total of 18 position papers were identified that related to topics under the theme of lifespan development.

1.1 At the gestation and birth end of the scale, one position paper⁵ advocated for more balanced information to be provided to expectant parents to help them make more informed choices with regards to pre-natal testing for disability, and decisions around whether or not to terminate a pregnancy.

1.2 At early childhood stage, three papers^{6 7 8} advocated full inclusion for children in early childhood education services, while the other paper promoted the importance of early intervention and developmental services⁹.

⁵ [PP 003] Down Syndrome Australia. (2017). *Position Paper on Prenatal Testing and Diagnosis*. Retrieved from https://www.downsyndrome.org.au/position_statements.html

⁶ [PP 049] Early Childhood Intervention Australia (ECIA) NSW/ACT. (2012). *Position Statement on the Inclusion of Children with Disability in Early Childhood Education and Care*. Retrieved from <https://www.ecia.org.au/Portals/4/Representation/Position%20Statements/ECIA%20ECA%20Join%20Inclusion%20Statement.pdf?ver=2018-06-06-152629-957>

⁷ [PP 054] Division for Early Childhood of the Council of Exceptional Children. (2015). *Position Statement: Leadership in Early Intervention and Early Childhood Special Education*. Retrieved from <https://www.decdocs.org/position-statement-leadership>

⁸ [PP 056] Division for Early Childhood of the Council of Exceptional Children. (2009). *Early Childhood Inclusion*. Retrieved from <https://www.decdocs.org/position-statement-inclusion>

⁹ [PP 031] The Arc. (2013). *Early Childhood Services*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

1.3 Five papers^{10 11 12 13 14} focused on the school years and predominantly promoted inclusion in mainstream classroom environments, including access to properly funded supports. One paper¹⁰ argued that children with Intellectual Disability (ID) should have access to free, high quality education with ambitious goals, challenging objectives, and individualised supports.

1.4 Only one paper¹⁵ focused on the transition from school to work, advocating the need for a planned and 'typical' transition to employment 'similar to other young people' beginning from the age of 14, and supported by the NDIS.

1.5 Three papers^{16 17 18} advocated the right of parents with ID to have children and raise them with support, and challenging societal assumptions that they are not capable of being parents. One paper¹² observed that parents with ID are 10 times more likely to have children removed from their care.

¹⁰ [PP 002] Down Syndrome Australia. (2017). *Position Paper on Education*. Retrieved from https://www.downsyndrome.org.au/documents/position_statements/Position_Statement_on_Education_Final_18.pdf

¹¹ [PP 104] Family Advocacy. (2016). *Inclusive Education: Family Advocacy Position Statement*. Retrieved from <https://www.family-advocacy.com/assets/b842834759/FA-position-statement-inclusive-education-2016.pdf>

¹² [PP 085] Validity. (2015). *All children have the right to inclusive education*. Retrieved from <https://validity.ngo/2015/09/08/all-children-have-the-right-to-inclusive-education/>

¹³ [PP 112] Inclusion International. (2008). *Position Paper – Education*. Retrieved from <https://inclusion-international.org/wp-content/uploads/2010/06/EDUCATION.pdf>

¹⁴ [PP 032] The Arc. (2018). *Education*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹⁵ [PP 069] NDS. (2019). *NDS Position Paper: Improving school-to-work transition through the NDIS*. Retrieved from <http://www.tickettowork.org.au/wp-content/uploads/2019/02/school-to-work-transition-paper.pdf>

¹⁶ [PP 007] Office of the Public Advocate (Victoria). (2012). *The removal of children from their parent with a disability*. Retrieved from <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/72-the-removal-of-children-from-their-parent-with-a-disability?path=>

1.6 Aging was addressed by three papers^{19 20 21}, one of which claimed that people with ID are particularly vulnerable to less equitable care and outcomes. One paper¹⁶ cited four principles: (1) dignity, (2) respect for autonomy, (3) life, and (4) equality. The papers argued that people with ID should be supported to age in place, and that there should be clear, consistent and ethically sound guidelines for end of life care.

1.7 One paper²² addressed the issue of assisted suicide (euthanasia), advocating that people with ID should be protected from all forms of physician-assisted suicide.

There were no position papers found that addressed wills or funerals.

¹⁷ [PP 039] The Arc. (2013). *Parents with Intellectual and/or Developmental Disabilities*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹⁸ [PP 121] International Association for the Scientific Study of Intellectual Disabilities (IASSID). (2008). *Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities*. Retrieved from <https://drive.google.com/file/d/0B2v4ukYuvZF9b01tYkx6ZVdNVmM/view>

¹⁹ [PP 029] The Arc. (2013). *Aging*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

²⁰ [PP 072] American Association of Intellectual & Developmental Disabilities (AAIDD). (2012). *Caring at End of Life*. Retrieved from <https://aaid.org/news-policy/policy/position-statements/caring-at-the-end-of-life>

²¹ [PP 121] International Association for the Scientific Study of Intellectual Disabilities (IASSID). (2008). *Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities*. Retrieved from <https://drive.google.com/file/d/0B2v4ukYuvZF9b01tYkx6ZVdNVmM/view>

²² [PP 024] The Arc. (2017). *Physician-assisted Suicide*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

Theme 2: Community Living

#	TOPIC	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10
2.1	Accommodation & independent living skills	PP 10	PP 36	PP 105							
2.2	Employment, career & volunteering	PP 33	PP 103								
2.3	Income security (inc DSP)	PP 38									
2.4	Lifelong learning (inc tertiary education)										
2.5	Transport	PP 42									
2.6	Leisure, holidays & travel										
2.7	Social inclusion	PP 62	PP 17	PP 23	PP 28	PP 70	PP 71	PP 84	PP 96	PP 100	

A total of 16 position papers were identified that addressed topics related to community living.

2.1 Three papers^{23 24 25} addressed the importance of funding for accessible and affordable community-based accommodation options that are of a high standard, with appropriate supports in place. One paper suggested that people with ID should also have the opportunity to purchase their own home²⁰.

2.2 One paper²⁶ advocated that people with ID should be employed in community settings and earn competitive wages. A second paper²⁷ expressed concern over changes to the funding model for disability employment services,

claiming that people with higher support needs were not being adequately supported by the system.

²³ [PP 010] Annual Round Table on Intellectual Disability Policy in Victoria. (2009). *Position statement on housing and support for people with severe or profound intellectual disability*. Retrieved from <https://scholars.latrobe.edu.au/display/publication17958>

²⁴ [PP 036] The Arc. (2017). *Housing*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

²⁵ [PP 105] Family Advocacy. (2016). *Housing Position Statement*. Retrieved from <https://www.family-advocacy.com/assets/Uploads/FA-Policies/Of3a996ba4/FA-Position-Statement-Housing-2014.pdf>

²⁶ [PP 033] The Arc. (2017). *Employment*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

²⁷ [PP 103] Disabled People's Organisations Australia. (2018). *Position Paper: Opposition to DES Funding Cuts for participants with higher support needs*. Retrieved from <https://dpoa.org.au/position-des-fund-cuts/>

2.3 One paper²⁸ advocated the right of people with ID to advance their economic and personal freedom through wealth creation (earning and saving money) and exercising decision-making over their funds.

2.5 Access to affordable public and private transport was promoted by one paper²⁹.

2.7 Nine papers^{30 31 32 33 34 35 36 37 38} highlighted the central importance of social inclusion in the lives of people with ID. In particular, that people should live in the community and not in institutions, that community-based services should not

emulate institutional practices, that women and children with ID should be afforded extra protections, that children should not be placed into group homes, and that the community should be educated about social inclusion.

There appeared to be gaps in the existing body of position papers in relation to lifelong learning (including the importance of people with ID studying at tertiary level or in adult community education), and in relation to leisure, going on holiday and travelling.

²⁸ [PP 038] The Arc. (2016). *Opportunities for Financial Asset Building*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

²⁹ [PP 042] The Arc. (2013). *Transportation*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

³⁰ [PP 062] Office of the Public Advocate (Victoria). (2013). *Congregate-care facilities (institutions) for people with a disability*. Retrieved from <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/social-inclusion/institutions/323-opa-position-statement-congregate-care-facilities-institutions-for-people-with-a-disability>

³¹ [PP 017] Office of the Public Advocate (Queensland). (2013). *Position Statement on Continuing the Deinstitutionalisation of People with Disability in Queensland*. Retrieved from https://www.justice.qld.gov.au/_data/assets/pdf_file/0009/203040/Position-Statement.pdf

³² [PP 023] The Arc. (2015). *Inclusion*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

³³ [PP 028] The Arc. (2014). *Life in the Community*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

³⁴ [PP 070] American Association of Intellectual & Developmental Disabilities (AAIDD). (2017). *Statement in Support of Diversity and Inclusion*. Retrieved from <http://aaidd.org/news-policy/policy/position-statements/statement-in-support-of-diversity-and-inclusion>

³⁵ [PP 071] American Association of Intellectual & Developmental Disabilities (AAIDD). (2016). *Community Living and Participation for People with Intellectual and Developmental Disabilities*. Retrieved from <http://aaidd.org/news-policy/policy/position-statements/community-living-and-participation>

³⁶ [PP 084] Validity. (2019). *All children have the right to family – joint position statement*. Retrieved from <https://validity.ngo/2019/07/09/all-children-have-the-right-to-family-joint-position-statement/>

³⁷ [PP 096] Mansell, J., & Beadle-Brown, J. (2010). *Deinstitutionalisation and community living: position statement of the comparative policy and practice special interest research group of the International Association for the Scientific Study of Intellectual Disabilities*. Journal of Intellectual Disability Research, 54(2), 104-112.

³⁸ [PP 100] Women With Disabilities Australia (WWDA). (2016). *WWDA Position Statement 3: The Right to Participation*. Retrieved from http://wwda.org.au/wp-content/uploads/2016/12/Position_Statement_3_-_Participation_FINAL_WEB.pdf

Theme 3: Individual Autonomy

#	TOPIC	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10
3.1	Communication & assisted decision-making	PP 1	PP 99	PP 110	PP 114						
3.2	Self-determination & self-advocacy (incl dignity of risk)	PP 20	PP 26	PP 27	PP 123						
3.3	Citizenship & civic involvement (incl voting)	PP 51									
3.4	Friendship and peer networks										
3.5	Mentoring, goal setting & social roles (incl volunteering)										
3.6	Personal development & leadership										
3.7	Access to information (incl easy-read)										

Nine position papers were identified related to the theme of individual autonomy.

3.1 Three papers^{39 40 41} declared that people with ID should have the right to make their own decisions, and have the capacity to do so with support. One of these papers³⁷ observed that the right to decision-making is fundamental to the realisation of agency, autonomy and self-determination. Concern was expressed that guardianship is often unnecessarily imposed, and it was suggested that

parents and carers need education and support to promote autonomous decision-making. Another paper⁴² advocated that people with ID should have access to adequate communication services and supports (such as communication devices and technologies).

3.2 Three papers^{43 44 45} from the same organisation were concerned with self-determination and self-advocacy, as well as people with ID being recognised before the law as having legal capacity to make decisions. One of these papers⁴⁰

³⁹ [PP 099] Women With Disabilities Australia (WWDA). (2016). **WWDA Position Statement 2: The Right to Decision-Making**. Retrieved from http://wwda.org.au/wp-content/uploads/2016/12/Position_Statement_2_-_Decision_Making_FINAL_WEB.pdf

⁴⁰ [PP 110] Inclusion Australia. (n.d.). **Decision Making**. Retrieved from <https://www.inclusionaustralia.org.au/about-us/our-voice/>

⁴¹ [PP 114] Inclusion International. (2008). **Key Elements of a System for Supported Decision Making**. Retrieved from https://inclusion-international.org/wp-content/uploads/2013/07/Position_Paper-Supported_Decision_Making.pdf

⁴² [PP 001] National Joint Committee for the Communication Needs of Persons with Severe Disabilities. (2003). **Position statement on access to communication services and supports:**

Concerns regarding the application of restrictive eligibility policies. Retrieved from <https://www.asha.org/policy/PS2003-00227/>

⁴³ [PP 020] The Arc. (2014). **Autonomy, Decision-Making Supports, and Guardianship**. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁴⁴ [PP 026] The Arc. (2014). **Self-Advocacy**. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁴⁵ [PP 027] The Arc. (2018). **Self-Determination**. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

suggested that people with ID have a right to be supported to act as self-advocates, communicating for and representing themselves. A fourth paper⁴⁶ argued that people with ID should be more involved in planning the services they use, and should be encouraged to speak up and to make a difference.

3.3 One paper⁴⁷ advocated that people with ID should be supported to engage in electoral voting by their service providers, but that low expectations and limited supports are common barriers.

This theme appeared to attract the least number of position papers, and yet could be considered the most important area in need of evidence-based material to support the voice and autonomy of people with ID. Part of developing a sense of autonomy is the capacity to cultivate friendships and peer networks, set goals, fulfil social roles, be mentored, engage in personal development and leadership development, and have access to information in accessible formats (eg. easy read). Gaps were found in each of these significant areas, as can be observed in the table above.

⁴⁶ [PP 123] Social Care Institute for Excellence (SCIE). (2007). *SCIE Position paper 6: Supporting self-advocacy*. Retrieved from <https://www.scie.org.uk/publications/positionpapers/pp06.asp>

⁴⁷ [PP 051] La Trobe University Living With Disability Research Centre. (2019). *Strategies to Support People with Intellectual Disabilities to Participate in Voting*. Retrieved from <http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:42631>

Theme 4: Health and Wellbeing

#	TOPIC	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10
4.1	Diagnosis, testing & early intervention	PP 15	PP 57	PP 58	PP 88						
4.2	Health care, disease prevention & management	PP 4	PP 6	PP 35	PP 55	PP 79	PP 80				
4.3	Hospital & specialist intervention	PP 59	PP 68								
4.4	Medication (treatment & management)										
4.5	Dental health	PP 102									
4.6	Sexuality, reproductive health & sterilisation	PP 40	PP 60	PP 64	PP 94	PP 97	PP 101	P125			
4.7	Mental health, wellbeing & spirituality	PP 41	PP 67								

A total of 22 position papers were identified related to the theme of health and wellbeing.

4.1 Of the four papers discussing diagnosis, testing and early intervention, two⁴⁸ cited a lack of consistency in diagnosis, practice and policy by paediatricians and therapists. Two papers^{50 51} advocated that teachers and nurses should be educated to identify and report signs of developmental delay as early as possible. One paper⁴⁶ highlighted the benefits and importance of early intervention.

⁴⁸ [PP 057] Canadian Paediatric Society. (2018). *Evaluation of the child with global developmental delay and intellectual disability*. Retrieved from <https://www.cps.ca/en/documents/position/evaluation-of-the-child-with-global-developmental-delay-and-intellectual-disability>

⁴⁹ [PP 088] RTI Action Network. (n.d.). *Position Statement on Determination of Specific Learning Disabilities*. Retrieved from <http://www.rtinetwork.org/about-us/position-statement-on-determination-of-specific-learning-disabilities>

⁵⁰ [PP 015] Royal Australasian College of Physicians. (2013). *Position Statement Early Intervention for Children with Developmental Disabilities*. Retrieved from <https://www.racp.edu.au/docs/default-source/advocacy-library/early-intervention-for-children-with-developmental-disabilities.pdf>

⁵¹ [PP 058] Society of Paediatric Nurses. (2014). *Position Statement on Early Childhood Development*. Retrieved from [https://www.pediatricnursing.org/article/S0882-5963\(13\)00364-3/fulltext#s0015](https://www.pediatricnursing.org/article/S0882-5963(13)00364-3/fulltext#s0015)

4.2 Six papers^{52 53 54 55 56 57} expressed concern with the inequitable treatment and health outcomes of people with ID by health care services, including avoidable deaths while in care. One paper⁵¹ expressed concern that children with ID are at greater risk of acquiring preventable secondary disabilities or exacerbation of their condition due to inadequate treatment. One paper⁵⁰ recommended that people with ID should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs, and maximises well-being and function.

4.3 Two papers were concerned with how people with ID were being managed in the hospital system. One of these papers⁵⁸ advocated better data collection to ensure treating staff could access historical information, and the other paper⁵⁹ advocated that people with ID should be identified as a priority group to enable a more appropriate response from treating staff.

4.5 One (somewhat dated) paper⁶⁰ expressed concern over the lack of planning around dental care for people with ID leaving institutional care.

⁵² [PP 004] NSW Council for Intellectual Disability. (2019). **Position Statement on Health**. Retrieved from <https://cid.org.au/resource/our-position-statement-on-health/>

⁵³ [PP 006] Professional Association of Nurses in Developmental Disability Australia. (2007). **Health and People with Developmental/Intellectual Disabilities**. Retrieved from http://www.pandda.net/files/PS_DD_Health_and_People.pdf

⁵⁴ [PP 035] The Arc. (2017). **Health**. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁵⁵ [PP 055] Division for Early Childhood of the Council of Exceptional Children. (2012). **Position Statement: Promoting the Health, Safety and Well-Being of Young Children with Disabilities and Developmental Delays**. Retrieved from <https://www.decdocs.org/executive-summary-promoting-health>

⁵⁶ [PP 079] Australian Association of Developmental Disability Medicine. (2015). **Position Statement on the Health of People with Intellectual Disability**. Retrieved from <https://aaddm.com.au/wp-content/uploads/AADDM-CID-Health-Position-Statement.pdf>

⁵⁷ [PP 080] Office of the Public Advocate (Queensland). (2019). **Position Statement: Upholding the Right to Life and Health of People with Disability**. Retrieved from https://www.justice.qld.gov.au/_data/assets/pdf_file/0010/618409/right-to-life-and-health-position-statement-final.pdf

⁵⁸ [PP 059] Agency for Clinical Innovation (NSW). (2014). **Position statement on the importance of a NSW intellectual disability data set**. Retrieved from https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0004/276817/position-statement-data-set.pdf

⁵⁹ [PP 068] NDS (NSW). (2014). **Creating Inclusive NSW Hospitals**. Retrieved from https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0005/307157/Creating_Inclusive_NSW_Hospitals.pdf

⁶⁰ [PP 102] Academy of Dentistry for Persons with Disabilities. (1998). **A Position Paper from the Academy of Dentistry for Persons with Disabilities: Preservation of quality oral health care services for people with developmental disabilities**. *Special Care in Dentistry*, 18(5), pp.180-182

4.6 Seven papers^{61 62 63 64 65 66 67} outlined rights in relation to sexuality and reproductive health, in particular that people with ID have a right to sexual intimacy and expression, and education, opportunities and support to explore their sexuality. One of these papers⁵⁸ expressed concern about a lack of protocols amongst service providers in reproductive and sexual health for people with ID. Three papers^{58 59 61} expressed strong arguments against forced sterilisation of women and girls with ID in non-life threatening situations, considered a violation of human rights. One newly released paper⁶³ calls for a policy clarifying the position of the NDIS in relation to funding, support and sexuality.

4.7 One paper⁶⁸ expressed concern that mental health policy can fail to recognise the specific needs of people with ID, and suggested that people with ID should be involved in the development of such policies. One paper⁶⁹ discussed spirituality, suggesting that people with ID have a right to choose their own expressions of spirituality, practice those beliefs, and participate in the faith community of their choice.

A gap was found in the administration and management of medications, such as over-prescription or lack of monitoring, and rights related to medication. Dental health also appeared to be an area overlooked in recent years in terms of position papers, such as the right to access affordable services and appropriately trained dentists.

⁶¹ [PP 040] The Arc. (2013). *Sexuality*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁶² [PP 060] Family Planning NSW. (2018). *Disability Position Paper*. Retrieved from https://www.fpnsw.org.au/sites/default/files/assets/Disability_Position_Paper_2018.pdf

⁶³ [PP 064] Office of the Public Advocate (Victoria). (2011). *Position Statement: The Sterilisation of Children*. Retrieved from <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/sterilisation/280-opa-position-statement-sterilisation-of-children-with-disability>

⁶⁴ [PP 094] Better Health (Government of Victoria). (2018). *Cognitive disability and sexuality*. Retrieved from <https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/intellectual-disability-and-sexuality>

⁶⁵ [PP 097] Women With Disabilities Australia (WWDA). (2016). *WWDA Position Statement 4: Sexual and Reproductive Rights*. Retrieved from http://wwda.org.au/wp-content/uploads/2016/10/Position_Statement_4_-_Sexual_and_Reproductive_Rights_FINAL_WEB.pdf

⁶⁶ [PP 101] Women With Disabilities Australia (WWDA). (2016). *WWDA Position Statement 4: Sexual and Reproductive Rights*. Retrieved from http://wwda.org.au/wp-content/uploads/2016/10/Position_Statement_4_-_Sexual_and_Reproductive_Rights_FINAL_WEB.pdf

⁶⁷ [PP 125] Disabled People's Organisations Australia. (2019). *Joint Position Statement: A call for a rights-based framework for sexuality in the NDIS*. Retrieved from <https://dpoa.org.au/joint-position-statement-a-call-for-a-rights-based-framework-for-sexuality-in-the-ndis/>

⁶⁸ [PP 067] UNSW. (2014). *Making Mental Health Policy Inclusive of People with Intellectual Disability*. Retrieved from https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0013/318001/Policy_analysis_Plain_English_Summary.pdf

⁶⁹ [PP 041] The Arc. (2015). *Spirituality*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

Theme 5: Rights & Advocacy

#	TOPIC	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10
5.1	Rights, quality of life, anti-discrimination, equal opportunity	PP 18	PP 19	PP 22	PP 37	PP 45	PP 109	PP 116	PP 117	PP 118	PP 120
5.2	Safeguards (against abuse, neglect, violence & harm)	PP 25	PP 61	PP 77	PP 95	PP 98					
5.3	Advocacy - family, citizen, professional	PP 106	PP 107	PP 108	PP 124						
5.4	Parent, carer & sibling support & education	PP 34	PP 93								
5.5	Legal, justice & guardianship	PP 12	PP 14	PP 21	PP 78	PP 82	PP 87	PP 115			
5.6	Aboriginal TSI, CALD, migrants & refugees, rural/remote	PP 50									
5.7	Research about & with PwID	PP 44	PP 46	PP 66	PP 83						

A total of 33 position papers addressed the topic of rights and advocacy.

5.1 The first topic incorporates ten papers^{70 71 72 73 74 75 76 77 78 79} covering rights and discrimination-related matters. Key points raised were that people with ID

have the same legal, human and civil rights as other members of the population, but may need protection and support to exercise these rights. One paper⁶⁸ argued that these rights must be honoured, protected, promoted, communicated and enforced. A key right is the opportunity for a full life in the

⁷⁰ [PP 018] The Arc. (2015). *Quality of Life*. Retrieved from <https://www.thearc.org/who-we-are/position-statements/quality-of-life/quality-of-life>

⁷¹ [PP 019] The Arc. (2014). *Rights*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁷² [PP 022] The Arc. (2015). *Human and Civil Rights*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁷³ [PP 037] The Arc. (2011). *Individual Supports*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁷⁴ [PP 045] The Arc. (2014). *Long Term Supports and Services*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁷⁵ [PP 109] Inclusion Australia. (n.d.). *Bullying and diversity through language: a new way of thinking about this issue*. Retrieved from <https://www.inclusionaustralia.org.au/about-us/our-voice/>

⁷⁶ [PP 116] Inclusion International. (2008). *Position Paper - "A Right to Life"*. Retrieved from https://inclusion-international.org/wp-content/uploads/2013/07/Position_Paper-A_Right_to_Life1.pdf

⁷⁷ [PP 117] Inclusion International. (2010). *Position Paper - Children*. Retrieved from <https://inclusion-international.org/wp-content/uploads/2013/08/positionpaperCHILDREN.pdf>

⁷⁸ [PP 118] Inclusion International. (2010). *Position Paper – Families*. Retrieved from <https://inclusion-international.org/wp-content/uploads/2010/06/FAMILY.pdf>

⁷⁹ [PP 120] Dimensions UK. (2016). *Position statement: hate crime towards people with learning disabilities and autism*. Retrieved from <https://www.dimensions-uk.org/news-blog-post/hate-crime-learning-disability-autism/>

community where they can live, learn, work and socialize, supported by a comprehensive, person-centred and nationalised system of support. However, people with ID face discriminatory attitudes and even hate crimes, and so society needs to think and speak differently about disability. Families and carers face discrimination by association and require recognition for their role in providing primary support.

5.2 Four papers^{80 81 82 83} recognised that people with ID are particularly vulnerable to abuse and neglect, and recommended a range of safeguards and a safeguarding framework under the NDIS. A fifth paper⁸⁴ looked at the issue of safeguarding people with ID against exposure to harmful or contaminated environments.

5.3 Four papers^{85 86 87 88} were concerned with the provision of independent and family advocacy. Two of these papers advocated a long-term funding base for independent advocacy services. A third paper called for the recognition of carers as effective advocates in service design, delivery and review. A fourth paper

expressed concern about governments making decisions on behalf of people with ID, and called for access to independent advocacy for decision-making.

5.4 Two papers^{89 90} discussed family support, suggesting that families caring for a person with ID should be strengthened and supported through family support services and other means, and observed that siblings are often overlooked and do not advocate well for themselves.

⁸⁰ [PP 025] The Arc. (2015). *Protection from mistreatment*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁸¹ [PP 061] Office of the Public Advocate (Victoria). (2016). *Position statement: Safeguards and the National Disability Insurance Scheme*. Retrieved from <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/ndis/ndis-safeguards/363-position-statement-word-safeguards-and-the-ndis>

⁸² [PP 098] Women With Disabilities Australia (WWDA). (2016). *WWDA Position Statement 1: The Right to Freedom From All Forms of Violence*. Retrieved from http://wwda.org.au/wp-content/uploads/2016/12/Position_Statement_1_-_Violence_FINAL_WEB.pdf

⁸³ [PP 095] NSW Council for Intellectual Disability. (2015). *Position Statement: NDIS Quality & Safeguarding Framework*. Retrieved from <https://engage.dss.gov.au/wp-content/uploads/2015/05/QS-NSWCID-posn-280415-final.pdf>

⁸⁴ [PP 077] American Association of Intellectual & Developmental Disabilities (AAIDD). (2012). *Environmental Health*. Retrieved from <https://aaidd.org/news-policy/policy/position-statements/environmental-health>

⁸⁵ [PP 106] NSW Council for Intellectual Disability. (2016). *Transfer of NSW government disability services to the non-government sector*. Retrieved from [https://www.family-](https://www.family-advocacy.com/assets/Uploads/News/d7e8765fe9/Joint-Position-Statement-ADHC-Tfer-6-5-16.pdf)

[advocacy.com/assets/Uploads/News/d7e8765fe9/Joint-Position-Statement-ADHC-Tfer-6-5-16.pdf](https://www.family-advocacy.com/assets/Uploads/News/d7e8765fe9/Joint-Position-Statement-ADHC-Tfer-6-5-16.pdf)

⁸⁶ [PP 107] NSW Council of Social Service: Disability Network Forum. (n.d.). *NSW Disability Network Forum Position Paper: Advocacy, Information and Representation*. Retrieved from <https://www.ncoss.org.au/policy/nsw-disability-network-forum-position-statement-advocacy-information-and-representation>

⁸⁷ [PP 108] Stand By Me. (2018). *Position Paper: Long term funding for disability advocacy*. Retrieved from <https://standbyme.org.au/wp-content/uploads/2019/05/Stand-By-Me-Position-Paper-April-2019.pdf>

⁸⁸ [PP 124] Social Care Institute for Excellence (SCIE). (2006). *Stakeholder Participation Position Paper 05: Working together: Carer participation in England, Wales and Northern Ireland*. Retrieved from <https://www.scie.org.uk/publications/positionpapers/pp05.pdf>

⁸⁹ [PP 034] The Arc. (2014). *Family Support*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁹⁰ [PP 093] Royal Australian and New Zealand College of Psychiatrists. (2011). *Addressing the needs of siblings of children with disability or chronic illness*. Retrieved from http://siblingsaustralia.org.au/wp-content/uploads/2017/10/69_PS_2011-Addressing-the-needs-of-siblings-of-children-with-disability-or-chronic-illness-RESCINDED.pdf

5.5 Aspects of legal, justice and guardianship concerns were covered by seven position papers^{91 92 93 94 95 96 97}. One paper⁸⁹ observed that people with ID who come into contact with the justice system face fear, prejudice, and a lack of understanding, and called for greater education for the legal fraternity. One paper⁹¹ suggested that people with ID do not enjoy equality before the law in the criminal justice system, and that each jurisdiction should develop an holistic, overarching response plan. People with ID may be held indefinitely without charge. Two papers advocate an end to this practice^{87 92}. One paper⁸⁸ suggested that those with mental health conditions placed on Supervised Treatment Orders by the courts require better safeguards. One paper⁹³ contended that guardianship laws make assumptions about capacity and unnecessarily introduce substitute decision-making provisions.

5.6 One paper⁹⁸ expressed concern that children in rural and remote areas were missing out on services, especially indigenous children.

5.7 Two papers^{99 100} called for more research to help prevent ID from occurring. A third paper¹⁰¹ called for more inclusive research design, and a fourth paper¹⁰² for stronger links between disability research and government policy.

Gaps were found in the areas of rights and advocacy in relation to Aboriginal and Torres Strait Islander, CALD, and migrants and refugees with ID. Also, in participatory forms of research.

⁹¹ [PP 012] Royal Australian and New Zealand College of Psychiatrists. (2016). *Principles for the treatment of persons found unfit to stand trial*. Retrieved from <https://www.ranzcp.org/news-policy/policy-submissions-reports/document-library/principles-for-the-treatment-of-persons-found-not>

⁹² [PP 014] Office of the Public Advocate (Victoria). (2010). *OPA position statement: Supervised Treatment Orders*. Retrieved from <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/282-opa-position-statement-supervised-treatment-orders?path=>

⁹³ [PP 021] The Arc. (2014). *Criminal Justice System*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

⁹⁴ [PP 078] Australian Association of Developmental Disability Medicine. (2017). *The Importance of Physical and Mental Health for People with Intellectual Disabilities in the Criminal Justice System*. Retrieved from <https://aaddm.com.au/wp-content/uploads/AADDM-The-Importance-of-Physical-and-Mental-Health-for-People-with-Intellectual-Disability-in-the-Criminal-Justice-System-Endorsement-August-2017.pdf>

⁹⁵ [PP 082] Australian Human Rights Commission. (2014). *Equal Before the Law: Towards Disability Justice Strategies*. Retrieved from <https://www.humanrights.gov.au/our-work/disability-rights/publications/equal-law>

⁹⁶ [PP 087] Queensland Advocacy Inc.. (2017). *QAI's position statement on the Forensic Disability Service*. Retrieved from <https://qai.org.au/wp-content/uploads/2017/10/Position-Statement-on-FDS.pdf>

⁹⁷ [PP 115] Inclusion International. (2008). *Position Paper- Legal Capacity*. Retrieved from <https://inclusion-international.org/wp-content/uploads/2010/05/Position-Paper-Legal-Capacity-June-2010.pdf>

⁹⁸ [PP 050] Royal Far West. (2017). *Position Paper: Supporting Childhood Development in Regional, Rural and Remote Australia*. Retrieved from <https://www.royalfarwest.org.au/wp-content/uploads/2018/09/RFW-Policy-Paper-Supporting-childhood-development-in-regional-and-rural-Australia-July-2017.pdf>

⁹⁹ [PP 044] The Arc. (2016). *Addressing the Causes and Effects of Intellectual and Developmental Disabilities*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹⁰⁰ [PP 046] The Arc. (2015). *Research*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹⁰¹ [PP 066] Agency for Clinical Innovation (NSW). (2014). *Guidelines on Research Inclusive of People with Intellectual Disability*. Retrieved from <https://www.aci.health.nsw.gov.au/resources/intellectual-disability/research/guidelines-research-id>

¹⁰² [PP 083] Australian Human Rights Commission. (2019). *Remember Disability Policy and Research Deals with the Everyday Lives*. Retrieved from <https://www.humanrights.gov.au/about/news/speeches/remember-disability-policy-and-research-deals-everyday-lives>

Theme 6: Service Approaches

#	TOPIC	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10
6.1	Consultation, feedback and complaint mechanisms	PP 111	PP 113	PP 119							
6.2	Paid support role, training & qualifications	PP 52	PP 75	PP 90							
6.3	Service planning & coordination (including person-centred)	PP 43	PP 47								
6.4	Funding management (incl self-management)										
6.5	Complex & unique support needs (incl dedifferentiation)	PP 8	PP 9								
6.6	Restrictive practices, challenging behaviours & positive behaviour support	PP 11	PP 30	PP 53	PP 63	PP 65	PP 73	PP 74	PP 76	PP 89	PP 92
6.7	Systems improvement, legislation & policy (incl NDIS)	PP 5	PP 13	PP 16	PP 48	PP 81	PP 86	PP 91			

A total of 27 position papers addressed service approaches.

6.1 Service user councils were advanced by three position papers^{103 104 105} as a means of involving people with ID in service development. One paper¹⁰¹ advocated that service users should be recognised as ‘experts by experience’. One paper⁹⁹ contended that service user councils should be evaluated for effectiveness.

6.2 Three papers discussed the role of paid support. One paper¹⁰⁶ advocated that they require training and support to improve quality, and better retention strategies. A second paper¹⁰⁷ called for training and guidance in advocacy, claiming that support workers can be primary advocates for their clients. A third paper¹⁰⁸ suggested that support staff should be trained in risk enablement, that is, supporting choice and control by providing clients opportunities take risks rather than trying to minimise risk.

¹⁰³ [PP 111] Social Care Institute for Excellence (SCIE). (2004). *Has service user participation made a difference to social care services?* Retrieved from <https://www.scie.org.uk/publications/positionpapers/pp03.pdf>

¹⁰⁴ [PP 113] Inclusion International. (2008). *Position Paper - User Councils*. Retrieved from https://inclusion-international.org/wp-content/uploads/2013/07/Position_Paper-User_Councils1.pdf

¹⁰⁵ [PP 119] British Psychological Society, Division of Clinical Psychology Faculty for People with Intellectual Disabilities. (2017). *Experts by Experience Position Statement and Strategy 2017-2018: Where we are now and our hopes for the future*. Retrieved from <https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Easy%20Read%20DRAFT%20DCP%20FPID%20Experts%20by%20Experience%20Position%20Statement%20and%20Strategy%20Nov%202018.pdf>

¹⁰⁶ [PP 075] American Association of Intellectual & Developmental Disabilities (AAIDD). (2016). *Direct Support Professionals (DSP) Workforce*. Retrieved from [http://aaid.org/news-policy/policy/position-statements/direct-support-professionals-\(dsp\)-workforce](http://aaid.org/news-policy/policy/position-statements/direct-support-professionals-(dsp)-workforce)

¹⁰⁷ [PP 090] VALID - Victorian Advocacy League for Individuals with Disability. (n.d.). *The Advocacy Role of Disability Support Workers*. Retrieved from https://www.valid.org.au/sites/default/files/position_statement_advocacy_role.pdf

¹⁰⁸ [PP 052] La Trobe University Living With Disability Research Centre. (2018). *The Essentials: Reframing disability support worker practice from risk aversion to risk enablement*. Retrieved from https://www.latrobe.edu.au/_data/assets/pdf_file/0007/954295/2018-LiDs-Research-poster-Risk-Enablement-website-BIGBY.pdf

6.3 Two papers^{109 110} related to service planning and coordination advocated that support coordination is a critical for helping people with ID to find and coordinate necessary services, and that enduring systems of support that are of high quality and focused on people with ID and their families enable them to live their lives like other people.

6.5 Two papers^{111 112} argued that people with complex support needs are not adequately recognised in general policy or supported across multiple service sectors, and that better definitions, data collection, and cross-sector policies and service responses are required. They termed this dedifferentiation.

6.6 Restrictive practices featured prominently in the present review, with ten papers^{113 114 115 116 117 118 119 120 121 122} developing positions against aversive

procedures as described as ‘behaviour support’. One paper¹⁰⁹ deemed restrictive practices as unethical, against human rights, ineffective, and a cause of physical and psychological harm for both the client and persons applying the practice. Papers made reference to eliminating electric shock treatment, the facilitated communication and rapid prompting methods, and the use of restraints and seclusion. One paper¹¹⁶ strongly endorsed the use of evidence-based practices. The education context was discussed by two papers^{111 113}, concluding that the system lacked legislative or policy guidance around the use of restrictive practices, and that such practices were limiting the social-emotional competence of children to facilitate inclusion. One paper¹¹⁰ advocated greater support for families around dealing with challenging behaviours in the home.

¹⁰⁹ [PP 043] The Arc. (2014). *Systems Summary*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹¹⁰ [PP 047] The Arc. (2015). *Support Coordination*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹¹¹ [PP 008] Australasian Society for Intellectual Disability. (2019). *Intellectual Disability and Complex Support Needs*. Retrieved from https://www.asid.asn.au/files/2460_background_paper_for_asid_position_statement_on_intellectual_disability_and_complex_support_needs.pdf

¹¹² [PP 009] Australasian Society for Intellectual Disability. (2018). *Addressing the shortcomings of Dedifferentiation*. Retrieved from https://www.asid.asn.au/files/1479_dedifferentiation_position_statement.pdf

¹¹³ [PP 011] Australasian Society for Intellectual Disability. (2010). *Official Position Statement Against the Use of Restrictive Practices in the Support of People who Have an Intellectual Disability*. Retrieved from https://www.asid.asn.au/files/708_2010_may_restrictive_practices.pdf

¹¹⁴ [PP 030] The Arc. (2015). *Behavioural Supports*. Retrieved from <https://www.thearc.org/who-we-are/position-statements>

¹¹⁵ [PP 053] Division for Early Childhood of the Council of Exceptional Children. (2017). *Position Statement on Challenging Behavior and Young Children*. Retrieved from <https://www.decdocs.org/position-statement-challenging-beha>

¹¹⁶ [PP 063] Office of the Public Advocate (Victoria). (2011). *Position Statement: Restrictive Interventions*. Retrieved from [https://www.publicadvocate.vic.gov.au/our-services/publications-](https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/mental-health/mental-health-facilities-research/300-opa-position-statement-restrictive-interventions-1)

[forms/research-reports/mental-health/mental-health-facilities-research/300-opa-position-statement-restrictive-interventions-1](https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/mental-health/mental-health-facilities-research/300-opa-position-statement-restrictive-interventions-1)

¹¹⁷ [PP 065] Office of the Public Advocate (Victoria). (2013). *Position statement: Restrictive interventions in educational settings*. Retrieved from <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/restrictive-interventions/41-restrictive-interventions-in-educational-settings>

¹¹⁸ [PP 073] American Association of Intellectual & Developmental Disabilities (AAIDD). (2012). *Aversive Procedures*. Retrieved from <http://aaid.org/news-policy/policy/position-statements/aversive-procedures>

¹¹⁹ [PP 074] American Association of Intellectual & Developmental Disabilities (AAIDD). (2019). *Electric Shock*. Retrieved from <http://aaid.org/news-policy/policy/position-statements/electric-shock>

¹²⁰ [PP 076] American Association of Intellectual & Developmental Disabilities (AAIDD). (2019). *Facilitated Communication and Rapid Prompting Method*. Retrieved from <http://aaid.org/news-policy/policy/position-statements/facilitated-communication-and-rapid-prompting-method>

¹²¹ [PP 089] VALID - Victorian Advocacy League for Individuals with Disability. (2012). *Facilitated Communication*. Retrieved from <https://www.valid.org.au/FCPosition>

¹²² [PP 092] Royal Australian and New Zealand College of Psychiatrists. (2016). *Minimising the use of seclusion and restraint in people with mental illness*. Retrieved from <https://www.ranzcp.org/news-policy/policy-submissions-reports/document-library/minimising-the-use-of-seclusion-and-restraint-in-p>

6.7 Seven papers^{123 124 125 126 127 128 129} dealt with systemic problems within the structures of funding and support, predominantly the NDIS, and the risk of some people falling through the gaps, such as children found not eligible for NDIS, or people with ID who lack informal networks, have a history of abuse, mental disorder, etc who would be eligible but may lack support to access the scheme. Two papers^{119 121} criticised the NDIS as not adequately focused on people with ID, lacking awareness, engaging in rushed and inconsistent planning, and as having

an unwieldy appeals process. Two papers^{13 91} called for greater collaboration between the NDIS and the health/medical sector.

Gaps were found in the areas of funding management (such as self-management), and in relation to the importance of consultation, feedback and complaint mechanisms.

¹²³ [PP 005] NSW Council for Intellectual Disability. (2015). *The NDIS and People with Intellectual Disability who Live on Society's Fringe*. Retrieved from <https://cid.org.au/resource/ndis-and-people-with-intellectual-disability-who-live-on-societys-fringe/>

¹²⁴ [PP 013] Royal Australasian College of Physicians. (2017). *Health and the National Disability Insurance Scheme: Position Statement*. Retrieved from <https://www.aph.gov.au/DocumentStore.ashx?id=e773331b-b0b7-4970-b75e-8a8fb48c50e3&subId=563975>

¹²⁵ [PP 016] NSW Council for Intellectual Disability. (2019). *Position Statement on the National Disability Insurance Scheme (NDIS)*. Retrieved from <https://cid.org.au/resource/our-position-statement-on-the-ndis-copy/>

¹²⁶ [PP 048] Early Childhood Intervention Australia (ECIA) NSW/ACT. (2018). *Position Paper: Gaps in Services for Children Age 0-6 with Developmental Delay and Disability*. Retrieved from

<https://www.ecia.org.au/Portals/4/Representation/Position%20Statements/Gaps-Position-Paper.pdf?ver=2018-07-23-135615-550>

¹²⁷ [PP 081] NSW Council for Intellectual Disability. (2019). *How to improve the NDIS for people with intellectual disability – CID position statement*. Retrieved from <http://www.nswcid.org.au/blog/how-to-improve-the-ndis-for-people-with-intellectual-disability.html>

¹²⁸ [PP 086] Australian Association of Social Workers (AASW). (2011). *Disability Position Paper*. Retrieved from <https://www.aasw.asn.au/document/item/2212>

¹²⁹ [PP 091] AMA - Australian Medical Association. (2018). *National Disability Insurance Scheme*. Retrieved from <https://ama.com.au/position-statement/national-disability-insurance-scheme-2018>

Discussion

This scoping review of position papers found a substantial number of papers, of variable quality. There appeared to be a lack of shared understanding and consistency about what constitutes a position paper (as opposed to a position statement, policy directive, discussion paper, research paper, and so forth). The better supported papers were explicit in their values and evidence base, and drew upon a variety of research papers, government or industry reports, and human rights conventions. Some also collaborated amongst multiple agencies, involved service-users or self-advocates, and/or were explicitly endorsed by multiple parties. Some used direct quotes from service users or collaborators. On the other hand, there were a number of position papers that did not do any of these things, but relied upon their status as a peak body or government agency as the evidence base for the information being presented. The vast majority of position papers were produced by industry peak bodies. Only two were written and produced entirely by self-advocates.

Of the 45 position papers catalogued, only six were available in easy-read formats. Three of these produced both easy-read and standard versions. One so-called easy-read version contained pictures and simple wording but was more than 20 pages long thus likely to diminish the intended effect of explaining the essence of the document in simple and succinct terms.

The position papers were generally not easy to find. They were often buried deep within agency websites under obscure links, and were likely not be accessed very often by the public. There is perhaps a need for a central repository of position papers related to ID. Some agencies numbered their position papers, both on the document and within the hyperlink, making it easy to locate and move between them by adjusting the number within the hyperlink. This way it was also easier to discover how many position papers a website contained.

Some websites published separate position papers and position statements. This appears to be good practice, as position papers typically provide more detailed analyses of the evidence, allowing the position statements to remain succinct.

Most of the more prolific organisations appeared to develop multiple position papers over a short period of time, and then stop. A small number appeared to periodically review and revisit their position statements, and in some cases rewrite them. However, it appeared that most organisations published their position papers and then did not revisit them or continue to develop new ones. One organisation in particular, The Arc based in the USA, had what could be described as a 'comprehensive' suite of position papers on their website. However, the vast majority of organisations developed less than three position papers. No organisation appeared to have an explicit strategy or list of topics that might be developed into position papers. Many organisations published groundwork documents such as submissions to government inquiries, or research and discussion papers that had the basic ingredients to be developed into position papers with some additional work. However, there appeared not to be any particular impetus, incentive or explicit strategy to invest in this additional work.

As outlined in the sections above, this scoping review identified a number of gaps in the current collection of position paper topics that could be explored for potential development into position papers. These include topics such as:

- lifelong learning, leisure, holiday and travel, friendships and peer networks, goal setting, social roles, mentoring, personal development and leadership development
- Aboriginal, Torres Strait Islander, CALD people, and migrants and refugees with ID
- consultation, feedback and complaint mechanisms, participatory research and access to information in accessible formats (eg. easy read)
- wills and funerals, administration and management of medications, dental health, funding management (such as self-management)

The next section will provide a set of recommendations for how ASID may wish to proceed.

Recommendations

ASID may wish to consider the following recommendations based on the findings of this scoping review:

1. *Publish and promote existing and future position papers in a prominent and easy to find section of the ASID website, preferably as part of a suite of supporting information such as discussion papers, news articles, multimedia vignettes, etc related to the particular topic.*
2. *Develop a naming and numbered URL convention for existing and future position papers.*
3. *Develop a system for regular review, updating or removal of existing position papers.*
4. *Practice and promote the use of easy-read versions of ASID position papers.*
5. *Separate position statements from position papers and publish them alongside each other.*
6. *Provide education, support and incentives for ASID members to develop position papers for various purposes, potentially in partnership with ASID and/or a university (eg. honours students may be invited to become involved in researching and drafting position papers as part of their honours research).*
7. *Publish a template and guidelines for how to present a position paper and/or position statement, for the benefit of ASID members and others.*
8. *Work with IASSID to develop and host an international repository of position papers. In the process, it may be advantageous to search the websites of IASSID member organisations for additional position papers (member organisations are not listed on their website, which means some may have been overlooked in the current scoping review).*

Conclusion

This scoping review has highlighted the significant body of evidence-based position papers that exists to advance the rights and wellbeing of people with intellectual disabilities living in Australia and Aotearoa New Zealand. It has established a baseline and provided a framework for further analysis of key themes and gaps in position papers, with a view to informing future development work. It has also clarified the difference between position papers, position statements and other types of documents, and recommends the development of a template and guidelines to support the work of any organisation seeking to develop their own position papers. Finally, this report has highlighted the present difficulties of accessing position papers and recommends that more work be done to establish a central repository or index of position papers, including easy-read versions.

Moving forward, ASID may wish to consider forming a partnership with The Arc in the United States to endorse some of their position papers, and/or use them as a starting point to develop new ASID position papers. The Arc can be contacted here: <https://thearc.org/about-us/contact-us/> and the key personnel can be found here: <https://thearc.org/about-us/board-senior-staff/>

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Appendix 1 – Annotated Bibliography

The annotated bibliography is in Excel format and lists all position papers by reference number, theme and topic. It contains summaries of the problem each position paper addresses, and the position it articulates. Also included are the types of evidence used, weblinks and notes.

	A	B	C	D	E	F	G	H	I	J	K	L	M
1	Annotated bibliography of position papers - September 2019												
2	ASID Scoping review of position papers that aim to enhance the lives of people with intellectual disability, prepared by Adam Johnson & Prof Kathy Boxall, Edith Cowan University												
3	This matrix lists each Position Paper by reference number, theme, and topic. Columns can be sorted using the drop-down arrows in the title bar. The matrix can also be keyword searched using Ctrl-F. Weblinks are also provided.												
4	Ref #	Theme	Topic	Subtopic	Year	Origin	Org	Title	Problem & Position Statement	Evidence Type	Web Link	Notes	Easy Read Available?
5	PP 001	3. Individual Autonomy	Communication & assisted decision-making	Improving access to communication supports	2003	USA	National Joint Committee for the Communication Needs of Persons with Severe Disabilities	Position statement on access to communication services and supports: Concerns regarding the application of restrictive eligibility policies. Position Paper on Education	Problem: PwID are not accessing adequate communication services and supports. Statement: It is the position of the National Joint Committee for the Communication Needs of Persons With Severe Disabilities that disabilities for communication services and supports should be based on individual needs. Problem: PwDs are not being educated in the same classrooms as their non-disabled peers. Statement: The purpose of this paper is to set out Down Syndrome Australia's (DSA) position on education for children with Down syndrome. This paper considers a range of factors relevant to assessment and decision-making for children with Down syndrome.	Academic papers - limited. Collaborative development. Developed by peak body.	https://www.asha.org/policy/PS2003-000377/		
6	PP 002	1. Lifespan Development	School years (incl mainstreaming)	Improving access to mainstream education	2017	Australia	Down Syndrome Australia	Position Paper on Education	Problem: PwDs are not being educated in the same classrooms as their non-disabled peers. Statement: The purpose of this paper is to set out Down Syndrome Australia's (DSA) position on education for children with Down syndrome. This paper considers a range of factors relevant to assessment and decision-making for children with Down syndrome.	Academic papers - extensive. Developed by peak body.	https://www.downsyndrome.org.au/docs/2017-09-20-Down%20Syndrome%20Position%20Paper%20on%20Education.pdf		Yes
7	PP 003	1. Lifespan Development	Gestation & birth	Improving pre-natal information	2017	Australia	Down Syndrome Australia	Position Paper on PreNatal Testing and Diagnosis	Problem: Parents are not receiving balanced pre-natal information to make an informed choice. Statement: The purpose of this paper is to set out Down Syndrome Australia's (DSA) position on prenatal testing (screening and diagnosis) for Down syndrome. This paper considers a range of factors relevant to assessment and decision-making for children with Down syndrome.	Academic papers - strong. Developed by peak body.	https://www.downsyndrome.org.au/policies/2017-09-20-Down%20Syndrome%20Position%20Paper%20on%20Prenatal%20Testing%20and%20Diagnosis.pdf		Yes
8	PP 004	4. Health & wellbeing	Health care, disease prevention & management	Improving access to health services	2019	Australia	NSW Council for Intellectual Disability	Position Statement on Health	Problem: PwID are not accessing health care services and health diagnoses equitably. Statement: "The standard of health care for most people with intellectual disability borders on neglect." (CID board member with intellectual disability).	Academic papers - strong. Developed by peak body.	https://cid.org.au/resources/our-repositioning-statement	A lot of easy-read resources available on this website, including an example of an easy-read position statement.	Yes
9	PP 005	6. Service approaches	Systems improvement, legislation & policy (incl NDIS)	Improving access to NDIS	2015	Australia	NSW Council for Intellectual Disability	The NDIS and People with Intellectual Disability who Live on Society's Fringe	Problem: PwID who lack informal networks, have history of abuse, mental disorder etc are not accessing the NDIS equitably. Statement: The design of the National Disability Insurance Scheme needs to carefully consider the circumstances of all people with disability.	Collaborative development.	http://www.nswcid.org.au/images/pdf/2015-05-20-NDIS%20and%20People%20with%20Intellectual%20Disability%20who%20Live%20on%20Society's%20Fringe.pdf	Link broken - unavailable	
10	PP 006	4. Health & wellbeing	Health care, disease prevention & management	Improving access to health services	2007	Australia	Professional Association of Nurses in Developmental Disability Australia	Health and People with Developmental/Intellectual Disabilities	Problem: The health system is not responding adequately or appropriately to the needs of PwID. Statement: This position paper has been developed by the Professional Association of Nurses in Developmental Disability Areas (PANDADA) in Australia, and contains 10 statements about the health needs of PwID.	Academic papers - extensive. Developed by peak body.	http://www.pandada.net/files/PANDADA_Health_and_People_with_Developmental_Disabilities.pdf		
11	PP 007	1. Lifespan Development	Parenting (with ID)	Improving support for parents with ID	2012	Australia	Office of the Public Advocate (Victoria)	The removal of children from their parent with a disability	Problem: A parent with ID are 10 times more likely to have children removed from their care. Statement: The Public Advocate supports the right of parents with a disability to live with and raise their children and believes they should receive encouragement and assistance from the community.	Academic papers - limited. Developed by government body.	https://www.publicadvocate.vic.gov.au/docs/2012-09-20-Parenting%20with%20ID.pdf		
12	PP 008	6. Service approaches	Complex & unique support needs (incl dedifferentiation)	Improving services for complex support needs	2019	Australia	Australasian Society for Intellectual Disability	Intellectual Disability and Complex Support Needs	Problem: PwID with complex support needs are receiving less equitable support from across different service sectors. Statement: Individuals with intellectual disability and complex support needs are currently not adequately recognised in policy or supported across multiple service sectors. To address this situation, the unique needs of PwID are not being adequately recognised or catered for in service provision.	Academic papers - extensive. Government/industry reports. Developed by peak body.	https://www.asid.asn.au/files/2019-05-20-Intellectual%20Disability%20and%20Complex%20Support%20Needs.pdf		
13	PP 009	6. Service approaches	Complex & unique support needs (incl dedifferentiation)	Recognising unique support needs of PwID	2018	Australia	Australasian Society for Intellectual Disability	Addressing the shortcomings of Dedifferentiation	Problem: The unique needs of PwID are not being adequately recognised or catered for in service provision. Statement: Recent international policy has prioritised 'dedifferentiation', which means inclusion of people with intellectual disabilities within the broader group of people with autism spectrum disorder.	Academic papers - extensive. Developed by peak body.	https://www.asid.asn.au/files/2018-05-20-Addressing%20the%20Shortcomings%20of%20Dedifferentiation.pdf		
14	PP 010	2. Community Living	Accommodation & independent living skills	Improving the provision of appropriate housing options	2009	Australia	Annual Round Table on Intellectual Disability Policy in Victoria	Position statement on housing and support for people with severe or profound intellectual disability	Problem: People with severe ID are at risk of not finding appropriately supported accommodation. Statement: A person with severe or profound intellectual disability should be able to expect standards and outcomes for housing and support that are equal to that of people with less severe ID.	Academic papers - extensive. Collaborative development.	https://sc.holters.latr.obe.edu.au/display/publication/2009-05-20-Position%20Statement%20on%20Housing%20and%20Support%20for%20People%20with%20Severe%20or%20Profound%20Intellectual%20Disability.pdf		
15	PP 011	6. Service approaches	Restrictive practices, challenging behaviours & positive behaviour	Reducing the prevalence of restrictive practices	2010	Australia	Australasian Society for Intellectual Disability	Official Position Statement Against the Use of Restrictive Practices in the Support of People who Have an Intellectual Disability	Problem: PwID are subjected to practices that cause physical and psychological harm and restrictions on freedoms and rights. Statement: ASSID Asserts that Restrictive Practices are: • Unethical & inconsistent with internationally accepted human rights.	Academic papers - strong. Developed by peak body.	https://www.asid.asn.au/files/2010-05-20-Official%20Position%20Statement%20Against%20the%20Use%20of%20Restrictive%20Practices%20in%20the%20Support%20of%20People%20who%20Have%20an%20Intellectual%20Disability.pdf	Good example of providing a summary of key points up front.	
16	PP 012	5. Rights & Advocacy	Legal, justice & guardianship	Preventing indefinite detention without trial	2016	ANZ	Royal Australian and New Zealand College of Psychiatrists	Principles for the treatment of persons found unfit to stand trial	Problem: PwID found unfit to stand trial are being held indefinitely in detention without conviction. Statement: Principle 1: Forensic patients must receive equity of access to health care and legal representation	Developed by peak body.	https://www.ranzcp.org/news/policy/policies/2016-05-20-Principles%20for%20the%20Treatment%20of%20Persons%20Found%20Unfit%20to%20Stand%20Trial.pdf	Good example of making principles explicit. Does not explain how the PS was developed.	

Image: Screenshot of the position paper annotated bibliography.

The annotated bibliography contains an index tab, as shown below. Each paper has been assigned a reference number (PP #).

The annotated bibliography can be downloaded here: <https://asidscopingreview.weebly.com/>.

Use this link to also access an electronic version of this report, and backup copies of the position papers.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P		
1	Index of Position Papers																	
2	ASID Scoping review of position papers that aim to enhance the lives of people with intellectual disability, prepared by Adam Johnson & Prof Kathy Boxall, Edith Cowan University																	
3	This index lists all position papers by theme and topic, and provides the PP (position paper) reference number (see tab called 'Position Papers')																	
4																		
5	#	THEME	TOPIC	# PAPERS	REF 1	REF 2	REF 3	REF 4	REF 5	REF 6	REF 7	REF 8	REF 9	REF 10				
6	1	LIFESPAN DEVELOPMENT		18														
7	1.1	Gestation & birth		1	PP 3													
8	1.2	Early childhood education & intervention		4	PP 31	PP 49	PP 54	PP 56										
9	1.3	School years (incl mainstreaming)		5	PP 2	PP 32	PP 85	PP 104	PP 112									
10	1.4	Post-school years (incl transition to)		1	PP 69													
11	1.5	Parenting (with ID)		3	PP 7	PP 39	PP 121											
12	1.6	Aging & aged care		3	PP 29	PP 72	PP 122											
13	1.7	Death, wills & funeral		1	PP 24													
14	2	COMMUNITY LIVING		16														
15	2.1	Accommodation & independent living skills		3	PP 10	PP 36	PP 105											
16	2.2	Employment, career & volunteering		2	PP 33	PP 103												
17	2.3	Income security (inc DSP)		1	PP 38													
18	2.4	Lifelong learning (inc tertiary education)																
19	2.5	Transport		1	PP 42													
20	2.6	Leisure, holidays & travel																
21	2.7	Social inclusion		9	PP 62	PP 17	PP 23	PP 28	PP 70	PP 71	PP 84	PP 96	PP 100					
22	3	INDIVIDUAL AUTONOMY		9														
23	3.1	Communication & assisted decision-making		4	PP 1	PP 99	PP 110	PP 114										
24	3.2	Self-determination & self-advocacy (incl dignity of risk)		3	PP 20	PP 26	PP 27											
25	3.3	Citizenship & civic involvement (incl voting)		1	PP 51													
26	3.4	Friendship																
27	3.5	Mentoring, goal setting & social roles (incl volunteering)																
28	3.6	Personal development & leadership		1	PP 123													
29	3.7	Access to information (incl easy-read)																
30	4	HEALTH & WELLBEING		21														
31	4.1	Diagnosis, testing & early intervention		4	PP 15	PP 57	PP 58	PP 88										
32	4.2	Health care, disease prevention & management		6	PP 4	PP 6	PP 35	PP 55	PP 79	PP 80								
33	4.3	Hospital & specialist intervention		2	PP 59	PP 68												
34	4.4	Medication (treatment & management)																
35	4.5	Dental health		1	PP 102													
36	4.6	Sexuality, reproductive health & sterilisation		6	PP 40	PP 60	PP 64	PP 94	PP 97	PP 101	PP 125							
37	4.7	Sexual health, relationships & consent		2	PP 41	PP 67												

Image: Screenshot of the position paper index.