



***Post-Polio Victoria Inc's  
Response to Australian Building Codes Board's  
Accessible Housing Options Paper***



**7 December, 2018**

### ***About Post-Polio Victoria (Inc)***

Post-Polio Victoria (Inc) (PPV) is a non-profit organisation that is run by a volunteer management committee consisting largely of people who have had polio.

PPV is committed to:

- assisting people with polio to stay connected to their community;
- advocating for post-polio needs to health professionals, services and government authorities; and
- providing information, advice and raising awareness of issues that surround polio to the broader community.

### ***Response to the ABCB Accessible Housing Options Paper***

In this *Response to the ABCB Accessible Housing Options Paper* PPV:

- Supplies evidence of the size of the Australian Post-Polio population, the unique trajectory of the polio disease, and our needs in relation to housing;
- Provides our choice of Option, from the ABCB's *Accessible Housing Options Paper*, and our rationale regarding what *minimum* level of Livable Housing Design (LHDG) standards should be incorporated into the *National Construction Code* – from the perspective of people experiencing the Late Effects of Polio (LEoP) and Post-Polio Syndrome (PPS);
- Provides Case Studies to inform the *Regulation Impact Statement (RIS)*;
- Supports calls for the Council of Australian Governments (COAG) to regulate a minimum accessibility standard for all new residential dwellings in Australia; and
- Argues that economic and statistical considerations and use of cost-benefit analyses should *not* be the *only* disciplines upon which minimum Livable Housing Design (LHDG) standards are decided.

PPV is in a unique position to offer reliable information on *both* the ageing *and also* the 'ageing-with-disability' populations.

## **Introduction**

At the public forum, Australian Building Codes Board's (ABCB's) Senior Project Officer, Kieran O'Donnell, stated that there had to be an identified, rational, quantifiable, rigorously demonstrated need in order for the *National Construction Code* to be revised:

*And we are trying to figure out what that need is...(and) how that unmet need is quantified... We need further evidence and information if we're going to be able to justify advising a regulatory change to the National Construction Code. (Hunter, quoted in Polio Oz News, Dec 2018).*

He stated that there was not much evidence available to support a case for revising the *National Construction Code* to include accessibility for ageing people; people living with disabilities; young families; people facing injury; or people living with illness. It seemed very obvious, to the people attending the consultation, that the ABCB would give a heavier weighting to quantitative evidence - of the sort provided by randomised clinical control studies and multiple regressions and accounting-based computations - than to the actual quality of the lived experience of all of the people whose lives would be affected by the decision on the m-i-n-i-m-u-m standards of housing design. Why not the 'optimum' standards of design to benefit the *whole of society*?

This approach immediately put ordinary taxpayers and citizens and polio survivors at a disadvantage, placing the *onus of proof onto us* to prove that we need a particular universal design level for housing. Rather than challenging the ABCB to prove why a particular standard of design that is *appropriate to the needs of the abovementioned populations* should *not be incorporated into the National Construction Code*.

In this Response to the ABCB's *Options Paper* PPV presents polio survivors' perspectives and lived experiences to inform the proposed revision of the *National Construction Code*. Evidence is provided of the size of the post-polio population, our needs, and Case Studies of how polio survivors have – or have not – attained appropriately accessible housing to match their needs, which can inform the *Regulation Impact Statement (RIS)*.

### ***Evidence on Late Effects of Polio (LEoP) and Post-Polio Syndrome (PPS)***

There is a well-developed body of literature on the complex phenomenon that is Polio, Late Effects of Polio (LEoP) and Post-Polio Syndrome (PPS) in quite diverse disciplines. These include: physical medicine and rehabilitation, neurological science, dentistry, orthopaedics, gerontology and geriatrics, psychology, geriatric sociology, Academy of Science, post-polio health, neurological management, Cochrane Database Systematic Review, rehabilitation nursing, neurobiology, rehabilitation research, clinical science, anesthesiology, accident research, physiotherapy, social science, and neuro-rehabilitation spheres of inquiry.

Areas of interest covered, by author:

- Ageing (Amtmann, Bamer et al, 2013; Heath, 2018; Kemp & Mosqueda, 2004; Laffont, Julia et al, 2014).

- Skeleto-muscular sequelae (Amtmann, Bamer et al, 2013; Berly, Strausser et al, 1991; Bruno, Johnson et al, 1985; Dalakas, 1995; Eulberg, 2012; Farbu, Gilhus et al, 2011; Farbu, Rekand et al, 2003; Gonzalez, Olsson et al, 2013; Halstead & Grimby, 1994; Halstead & Rossi, 1985; Lonnberg, 1993; March of Dimes International Conference on Post Polio Syndrome, 2000; Mohammad, Khan et al, 2009; Parliament of Australia, 2012; Post-polio Health International, 2012a, 2012b, 2012c; Tersteeg, Koopman et al, 2011; Trojan, & Cashman, 1997; Westbrook, 1991, 1996; World Health Organisation, 2011, 2018).
- Neurological sequelae (Jubelt & Cashman, 1986; Rekand, Albrektsen et al, 2000; Soderholm, Lehtinen et al, 2010; Wiechers & Hubbell, 1981)
- Falls (Bickerstaffe, Beelen et al, 2010; Cumming, Thomas, et al, 1999; Gillespie, Robertson et al, 2012; Monash University Accident Research Centre, 2008; Sherrington, Whitney et al, 2008; Silver & Aiello, 2002)
- Psychological considerations (Bruno & Frick, 1991; Conrady, Wish et al, 1989; Harrison & Stuijbergen, 2006; Jung, Broman et al, 2014; Kemp, Adams et al, 1997; Kemp & Krause, 1999; Rekand, Korv et al, 2004; Tate, Forchheimer et al, 1999; Yelnik & Laffont, 2010)
- Surgical considerations e.g. anaesthesia (Lambert, Giannouli et al, 2005)
- Sleep disturbance (Dahan, Kimoff et al, 2006)
- Dental complications (Bruno, 1996)
- Effects on families (Silver; 2001)

These are some of the symptoms polio survivors experience:

- muscle weakness and atrophy,
- fatigue,
- pain,
- respiratory complications/insufficiency,
- sleep disturbance,
- swallowing difficulties (dysphagia) and speech difficulties (dysarthria);
- impaired thermoregulation,
- bladder dysfunction,
- surgical considerations (anaesthetics),
- falls,
- psychological considerations,
- pharmacological considerations (summary of Cochrane Review),

- comorbidity considerations,
- ageing.

It is easy to see why accessible housing might be required for successfully dealing with some of these problems.

It has been estimated that 400,000 people in Australia caught polio in past epidemics of the enterovirus (Julelt & Agre, 2000; Farbu, Gilhus et al, 2011. See also poliohealth.org.au for population estimates).

Respiratory involvement is fatal in 5–10% of patients, and 1 in 200 patients develop long-term asymmetric paralysis (Jubelt & Agre, 2000). According to Koopman & Uegaki (2015) over half of those who contracted polio, even in different countries, will, at some stage, experience Late Effects of Polio.

It is estimated that there are 40,000 Australians who contracted paralytic polio (see poliohealth.org.au). These people are likely to be the ones who need high-level accessible housing, especially if they are experiencing LEOp/PPS.

Yet awareness of polio by healthcare providers is non-existent, or minimal, and little attention is paid to how LEOp and PPS affect survivors' quality of life and support systems (Dorsett & Woodbridge, 2016). Some government policies may, indeed, be counter-productive for polio survivors: 'for someone with post-polio, the notion of "active ageing" takes on a different meaning to those who have enjoyed good health throughout life. For people with post-polio the move to a more inclusive world is still elusive but essential....Universal design thinking makes the links because *the experience of the user is considered*, whereas access codes focus on the compliance checklist that needs to be signed off by a certifier' (Bringolf, 2016).

Heath's groundbreaking mixed-methods PhD, *Extending the Concept of Successful Ageing to Persons Ageing with Disabilities*, provides evidence of relevance to this consultation. Study One used qualitative methods to determine important issues in older Australian participants' lives who experienced either post-polio syndrome (PPS) or a spinal cord injury (SCI) (n=17). This resulted in a model with 8 dimensions: 'with either post-polio syndrome (PPS) or a spinal cord injury (SCI)' or not living with a disability. 'These were then used as a basis for developing a preliminary model of successful ageing which aims to provide a more inclusive and holistic approach, recognising the position of adults ageing with disabilities within a broader socio-political environment' (Heath, 2018:14).

Domains:

- 1) Looking after physical health;
- 2) Retaining cognitive abilities;
- 3) Positive psychological resources;
- 4) Retaining a sense of independence and autonomy;
- 5) Social engagement and participation in community;
- 6) Retaining a sense of purpose;
- 7) Fairness, respect and recognition; and
- 8) Safety and security.

'The preliminary model developed in Study One was then tested using a quantitative approach in Study Two...to replicate the qualitative results in a broader population of older adults ageing with a disability. Additionally the study sought to examine where differences and similarities were observed in perceptions of successful ageing factors between those ageing with and without a disability' (Heath, 2018:20). Study Two was an international online survey of participants from 14 countries.

Heath used hierarchical multiple regression analyses, bilateral correlations and moderation analyses to test the influence and predictive capabilities of the variables among Study Two participants (n=194 living *with disability*, n=73 living *without a disability*), relating to the domains identified in Study One. The findings of Study Two confirmed that the factors considered important for successful ageing are remarkably similar across both populations. Perhaps unsurprisingly, people living with a disability (PWD) found 'Retaining a sense of independence and autonomy' to be the most important domain to them (71.6%), followed by 'Looking after physical health' (71.1%) and 'Safety and security' (69.1%). These domains have relevance to this consultation, since accessible housing, that was suited to their needs, would be essential. Ageing people living without disability – who are still likely to want some accessibility features, gave precedence to 'Looking after physical health' (80.3%); 'Positive psychological resources' (79.8%); and 'Retaining a sense of purpose' (75.7%) (Heath, 2018:200)

Of particular note was 'having access to adequate income and secure housing that is tailored to current and future mobility and disability needs....(and) being able to access assistance to remain in their own homes for as long as possible.... was mentioned by three quarters of participants (Heath, 2018: 128, 130, 145)

*"...losing my environment, ... is one of the things I actually fear most" (M/SCI/50).*

As part of this, participants raised the need for appropriate supported housing options to be available for older people with disabilities as they age and their conditions potentially worsen:

*"...it's people like myself, who want to stay in their own home for as long as they can, that I can still get the equipment I need" (F/PPS/70).*

*"...success for me is to be still living in my own home maybe 10 or 15 years from now. And being able to do stuff. That's fairytales to me." (F/PPS/60)' (Heath, 2018:130).*

By contrast, 'an inadequate income and insecure housing options creates a sense of uncertainty and vulnerability that affects an individual's capacity to actively engage and participate in society' (Heath, 2018:146), thus exacerbating polio survivors' marginalisation. This supported Clarke & Latham's (2014) and Foster & Walker's (2015) research on the importance of socioeconomic status. This goes against COAG's and the National Dialogue's original purpose in convening the potential revision of the *National Construction Code* and the 'aspirational target' of the *National Disability Strategy 2010-2020*:

'The intent of the design principles of the LHDG is to provide homes that are easier and safer to use for all occupants, including people with a disability, the aged, people with temporary injuries and families with young children. According to the LHDG, a home designed using its principles is easy to enter, easy to navigate in and around, capable of

*Post-Polio Victoria Inc's*

*Response to Australian Building Codes Board's Accessible Housing Options Paper*  
© Barbary Clarke, PPV Policy Working Group

easy and cost-effective adaptation and responsive to the changing needs of home occupants (ABCB, Sep 2018:7)

It is possible that the salience of lower socioeconomic status for participants in Study One, 'reflects not only the likely reduced earning capacity during middle age for participants with a disability, a factor which ultimately impacts their level of savings as they enter old age but also their increased reliance on government funding sources and external providers...many of which are being progressively scaled back...as governments seek to limit their financial exposure to an ageing population (Heath, 2018:145-146).

***If it has taken 10 years for 5% of new houses to be built to Silver Level Livable Housing Design, will it take 200 years for 100% of new dwellings to be built to Silver, or Gold, Levels?***

In 2011 COAG wrote: 'An aspirational target that all new homes will be of agreed universal design standards by 2020 has been set, with interim targets and earlier completion dates to be determined' Council of Australian Governments (COAG). (Feb 2011:8)

PPV will not reiterate the position of the Australian Network for Universal Housing Design (ANUHD) - a position with which we agree - regarding regulation of a minimum standard of Accessible Housing. Save to say that it is disappointing that a seeming lack of political will, perhaps combined with the commercial interests of developers and builders who apparently do a lucrative trade in retrofits, have led to so little progress towards the 'aspirational goal' of 100% Silver Level new builds in the past 9 years.

Based on the Option 3 scenario:

*Option 3* - Weighted Average cost for Class 1a new builds: \$20,710

*Option 3* - Weighted Average cost for Class 2 new builds: \$28,766 (ABCB, 2018:28)

If, as the LHDG suggests, falls, alone, cost \$1.8 billion p.a. in public health costs (Monash University Accident Research Centre, 2008), then there could, for the same cost, be many, many dwellings built to Option 3 standard (86.93 million class 1a dwellings, or 62.6 million class 2 dwellings).

'Aspirational' goals have not proven to be worth the paper they're written on. Polio survivors *cannot wait* for accessible housing. The Silver - or preferably the Gold Level - must be regulated at once, rather than maintained on a voluntary basis in the *National Construction Code*. Measurable milestones should be monitored by an independent authority.

***Commentary on Case Studies and Recommended Options***

Post-Polio Victoria (Inc) members, and members of two Victorian Post-Polio Support Groups were requested to provide evidence of their experiences with housing accessibility.

Livable housing aims to 'provide homes that are easier and safer to use for all occupants, including people with a disability, the aged, people with temporary injuries and families with young children. According to the LHDG, a home designed using its principles is easy to

*Post-Polio Victoria Inc's  
Response to Australian Building Codes Board's Accessible Housing Options Paper  
© Barbary Clarke, PPV Policy Working Group*

enter, easy to navigate in and around, capable of easy and cost-effective adaptation and responsive to the changing needs of home occupants' (ABCB, 2018:7). The Case Studies in *Appendix One* demonstrate quite clearly that the Silver Level, per se, is inappropriate for the needs of polio survivors (or indeed others using wheelchairs). There are problems with lack of specification of room dimensions, even in the extended Silver Level in Option 2.

Case Study 1 confides that she is quite happy with retrofitting paid for by MyAgedCare, but would not be able to use the kitchen, without retrofitting, if she were permanently bound to a wheelchair

Case Study 2 requests 5 features that are not available at Silver Level. (See NSL – Not in Silver Level = code in body of Case Studies).

Case Study 3 has had multiple accessibility problems with her flat, even though it could officially be classified as Silver Level. She needs additional features as she ages (See NSL- Not in Silver Level - code in case Study section).

Case Study 4 has had retrofitted modifications made to a 1910 home's main bathroom, en suite, kitchen, and flooring. These were self-funded because obtaining funding from NDIS could not have been obtained to fit in to the building schedule. The house is still somewhat inaccessible, due to inability to construct suitable-gradient ramps to front and back doors, and narrow doors in four rooms, which prohibit wheelchair access.

Case Study 5 is happy with how her Housing Commission house was built (supposedly as accessible), except for the kitchen, where benches had to be lowered for wheelchair accessibility.

Case Study 6 has been a disaster from start to finish, demonstrating the perils of being an owner-builder - and the need to have Gold Level stipulated as the minimum standard for new builds.

Case Study 7 is unclear whether, after self-retrofit, she would prefer to have more accessibility features if she were able to have them funded. Possible unmet need.

Although the builder in Townsville (Case Study 8) is well-intentioned, it is a bit alarming that he is requesting a subsidy to build all new houses to Silver Level. Maybe he envisages that this would replace the business he will lose from lucrative retrofits.

## **Conclusion**

Based on the evidence presented in our Case Studies it is apparent that mandating that all new dwellings are built to Silver Level will leave quite an amount of unmet needs in the polio survivor – and other wheelchair-bound and disabled and ageing – populations.

We therefore recommend that the Gold Level, possibly with some additions from Platinum Level (e.g. bedroom dimensions) should be the minimum standard incorporated into the *National Construction Code*.

We dedicate this response to the late Margaret Cooper, who would have written it, if she had lived.

*Post-Polio Victoria Inc's  
Response to Australian Building Codes Board's Accessible Housing Options Paper  
© Barbary Clarke, PPV Policy Working Group*

## References

Amtmann, D., Bamer, A. M., Verral, A., Salam, R., & Borson, S. (2013) Symptom profiles of individuals ageing with post-polio syndrome. *Journal of the American Geriatrics Society*, 61(10), 1813-1815.

Australian Building Codes Board (Sep 2018). *Accessible Housing Options Paper*

Berly, M. H., Strausser, W. W., & Hall, K. M. (1991). Fatigue in post-polio syndrome. *Archives of Physical Medicine and Rehabilitation*, 72, 115-118.

Bertolasi L, Acler M, Dall'ora E et al. (2012). Risk factors for post-polio syndrome among an Italian population: a case-control study. *Neurol Sci*.

Bickerstaffe A, Beelen A, Nollet F. (2010). Circumstances and consequences of falls in polio survivors. *J Rehabil Med* 42(10):908-915.

Bringolf, J. (2016). Universal design: beyond the access codes *Proceedings of the 2016 Australasia-Pacific Post-Polio Conference: Polio – Life Stage Matters*, accessed at <https://www.poliohealth.org.au/wp-content/uploads/Sydney-Post-Polio-Conference>

Bruno RL. (1996). Preventing complications in polio survivors undergoing dental procedures. *Post-Polio Sequelea Monograph Series* 6(1):1-8.

Bruno RL, Frick NM. (1991). The psychology of polio as prelude to post-polio sequelae: behaviour modification and psychotherapy. *Orthopedics* 14(11):1185-1193.

Bruno RL, Johnson JC, Berman WS. (1985). Vasomotor abnormalities as post-polio sequelae: functional and clinical implications. *Orthopedics* 8(7):865-869.

Clarke, P., & Latham, K. (2014). Life course health and socioeconomic profiles of Americans ageing with disability. *Disability Health Journal*, 7(1), S15-23. doi: 10.1016/j.dhjo.2013.08.008

Conrady, L. J., Wish, J. R., Agre, J. C., Rodriguez, A. A., & Sperling, K. B. (1989). Psychologic characteristics of polio survivors: a preliminary report. *Depression*, 50, 45-5.

Cooper, M., (2016). What is happening to patients who have had polio? The role of the patient in assessment and management. *Australian Family Practitioner*, 45(7): 529-530

Cooper M, & Bigby C. (2014) Cycles of adaptive strategies over the life course. *Journal of Gerontological Social Work*, 57(5):421–37.

Council of Australian Governments (COAG). (Feb 2011) *National Disability Strategy 2010-2020*.

Cumming RG, Thomas M, Szonyi G et al. (1999). Home visits by an occupational therapist for assessment and modification of environmental hazards: a randomized trial of falls prevention. *J Am Geriatr Soc* 47(12):1397-1402.

*Post-Polio Victoria Inc's  
Response to Australian Building Codes Board's Accessible Housing Options Paper  
© Barbary Clarke, PPV Policy Working Group*

- Dahan V, Kimoff RJ, Petrof BJ, Benedetti A, Diorio D, Trojan DA. (2006). Sleep-disordered breathing in fatigued postpoliomyelitis clinic patients. *Arch Phys Med Rehabil* 87(10):1352-1356.
- Dalakas MC. (1995). The post-polio syndrome as an evolved clinical entity. Definition and clinical description. *Ann N Y Acad Sci* 753:68-80.
- Dorsett, P., & Woodbridge, S. (2016). The lived experiences of older people with Post-Polio syndrome in Australia. *Proceedings of the 2016 Australasia-Pacific Post-Polio Conference: Polio – Life Stage Matters*, accessed at <https://www.poliohealth.org.au/wp-content/uploads/Sydney-Post-Polio-Conference>
- Eulberg MK. (2012). What having had polio causes, might cause and does not cause. *Post Polio Health* 28(2):1-5
- Farbu E, Gilhus NE, Barnes MP et al. Post-polio syndrome. In: Gilhus NE, Barnes MP, Brainin M, editors. *European Handbook of Neurological Management*. 2nd ed. Wiley-Blackwell; 2011:311-319.
- Farbu E, Rekand T, Gilhus NE. (2003). Post-polio syndrome and total health status in a prospective hospital study. *Eur J Neurol* 10(4):407-413.
- Foster, L., & Walker, A. (2015). Active and successful ageing: A European policy perspective. *The Gerontologist*, 55(1),83-90.
- Gillespie LD, Robertson MC, Gillespie WJ et al. (2012). Interventions for preventing falls in older people living in the community. *Cochrane Database Syst Rev* 9:CD007146.
- Gonzalez H, Olsson T, Borg K. (2010). Management of postpolio syndrome. *Lancet Neurol* 9(6):634-642.
- Halstead, L. S., & Grimby, G. (eds). (1994). *Post-Polio Syndrome*. Philadelphia: Hanley and Belfus, Inc.,
- Halstead LS, Rossi CD. (1985). New problems in old polio patients: results of a survey of 539 polio survivors. *Orthopedics* 8(7):845-850.
- Harrison, T. C., & Stuijbergen, A. K. (2006). Life purpose: effect on functional decline and quality of life in polio survivors. *Rehabilitation Nursing*, 31(4), 149-154.
- Heath, N.A., (2018). *Extending the Concept of Successful Ageing to Persons Ageing with Disabilities*, Unpublished PhD., University of Melbourne
- Ho, P., Kroll, T., Kehn, M., Anderson, P., & Pearson, K. M. (2007). Health and housing among low-income adults with physical disabilities. *Journal of Health Care For The Poor And Underserved*, 18(4), 902-915.
- Hunter, L., (30 Oct 2018). Changes to Accessibility Housing Standards, *Polio Oz News*, Dec 2018, Summer Edition 8(4):12-13

- Jubelt, B., & Agre, J.C., (2000). Characteristics and management of post-polio syndrome. *Journal of the American Medical Association (JAMA)*, 284(4):412–14.
- Jubelt B, Cashman NR. (1987) Neurological manifestations of the post-polio syndrome. *Crit Rev Neurobiol* 3(3):199-220.
- Jung, T-D., Broman, L., Stibrant-Sunnerhagen, K., Gonzalez, H., & Borg, K. (2014). Quality of life in Swedish patients with post-polio syndrome with a focus on age and sex. *International Journal of Rehabilitation Research*, 37, 173-179.
- Kemp, B. J., Adams, B. M., & Campbell, M. L. (1997). Depression and life satisfaction in ageing polio survivors versus age-matched controls: relation to post-polio syndrome, family functioning, and attitude toward disability. *Archives of Physical Medicine and Rehabilitation*, 78(2), 187-192.
- Kemp, B. J., & Krause, J. S. (1999). Depression and life satisfaction among people ageing with post-polio and spinal cord injury. *Disability and Rehabilitation*, 21(5:6), 241–249.
- Kemp, B., & Mosqueda, L. A. (Eds.). (2004). *Ageing with a disability: What the clinician needs to know*. JHU Press.
- Koopman, F.S., Uegaki, K., Gilhus, N.E., Beelen, A., de Visser, M., & Nollet, F. (2015). Treatment for postpolio syndrome. *Cochrane Database Systematic Reviews*, 5:CD007818.
- Laffont, I., Julia, M., Tiffreau, V., Yelnik, A., Herisson, C., & Pelissier, J. (2010). Ageing and sequelae of poliomyelitis. *Annals of Physical and Rehabilitation Medicine*, 53, 24-33.
- Lambert DA, Giannouli E, Schmidt BJ. (2005) Postpolio syndrome and anesthesia. *Anesthesiology* 103(3):638-644.
- Livable Housing Australia, *Livable Housing Design Guidelines*, 4th edition, 2017.
- Lonnberg F. (1993). Late onset polio sequelae in Denmark. Results of a nationwide survey of 3,607 polio survivors. *Scand J Rehabil Med Suppl* 28:1-32.
- March of Dimes International Conference on Post Polio Syndrome: Identifying best practice and care.*: March of Dimes 2000.
- Mohammad AF, Khan KA, Galvin L, Hardiman O, O'Connell PG. (2009). High incidence of osteoporosis and fractures in an aging post-polio population. *Eur Neurol* 62(6):369-374.
- Monash University Accident Research Centre. (2008) *The relationship between slips, trips and falls and the design and construction of buildings*. (Funded by the Australian Building Codes Board).
- Parliament of Australia. (2012). Chapter 2: Issues and Conclusions, Section 2.19. *Roundtable on Late Effects of Polio/Post-Polio Syndrome Report of the House Standing Committee on Health and Ageing Committee*.

Post-polio Health International. (2012a). Handbook on the late effects of poliomyelitis for physicians and polio survivors: Pulmonary function tests. <http://www.postpolio.org/edu/handbk/pulm.html>

Post-polio Health International. (2012b) Handbook on the late effects of poliomyelitis for physicians and polio survivors: Swallowing. <http://www.post-polio.org/edu/handbk/pulm.html>.

Post-polio Health International. (2012c). Post polio Health Care. <http://www.postpolio.org/edu/healthcare/PostPolioHealthCareAll.pdf>

Rekand T, Albrektsen G, Langeland N, Aarli JA. (2000). Risk of symptoms related to late effects of poliomyelitis. *Acta Neurol Scand* 101(3):153-158.

Rekand T, Korv J, Farbu E et al. (2004). Lifestyle and late effects after poliomyelitis. A risk factor study of two populations. *Acta Neurol Scand* 109(2):120-125.

Sherrington C, Whitney JC, Lord SR, Herbert RD, Cumming RG, Close JC.(2008). Effective exercise for the prevention of falls: a systematic review and meta-analysis. *J Am Geriatr Soc* 56(12):2234-2243.

Silver J.( 20010. *Post-Polio Syndrome: A guide for polio survivors and their families*. New Haven: Yale University Press.

Silver JK, Aiello D.D. (2002) Polio survivors: falls and subsequent injuries. *Am J Phys Med Rehabil* 81(8):567-570.

Soderholm S, Lehtinen A, Valtonen K, Ylinen A. (2010). Dysphagia and dysphonia among persons with post-polio syndrome - a challenge in neurorehabilitation. *Acta Neurol Scand* 122(5):343-349.

Tate, D. G., Forchheimer, M., Kirrsch, N., Maynard, F., & Roller, A. (1999). Prevalence and associated features of depression and psychological distress in polio survivors. *Archives of Physical Medicine and Rehabilitation*, 74, 1056-1060.

Tersteeg IM, Koopman FS, Stolwijk-Swuste JM, Beelen A, Nollet F. (2011). A 5-year longitudinal study of fatigue in patients with late-onset sequelae of poliomyelitis. *Arch Phys Med Rehabil* 92(6):899-904.

The global polio eradication initiative. Polio and Prevention. <http://www.polioeradication.org/polioandprevention.aspx>, 2012.

Trojan, D. A., & Cashman, N. R. (1997). Pathophysiology and diagnosis of post-polio syndrome. *NeuroRehabilitation*, 8(2), 83-92. doi. 10.3233/NRE-1997-8203.

Westbrook M. (1991). A survey of post-poliomyelitis sequelae: Manifestations, effects on people's lives and responses to treatment. *Aust J Physio* 37(2):89-102.

Westbrook M. (1996). Living with the late effects of disability: A five-year follow-up survey of coping among post-polio survivors. *Australian Occupational Therapy Journal* 43:60-71.

Wiechers D. O., & Hubbell, S. L. (1981). Late changes in the motor unit after acute poliomyelitis. *Muscle Nerve*, 4, 524–8.

World Health Organisation. (2011). World report on disability. Retrieved from: [http://whqlibdoc.who.int/hq/2011/WHO\\_NMH\\_VIP\\_11.01\\_eng.pdf?ua=1](http://whqlibdoc.who.int/hq/2011/WHO_NMH_VIP_11.01_eng.pdf?ua=1) on 05/05/2015.

World Health Organisation. (2018). Disability and Health factsheet. Retrieved from: <http://www.who.int/mediacentre/factsheets/fs352/en/> on 31/03/2018.

Yelnik A, Laffont I. 2010). The psychological aspects of polio survivors through their life experience. *Ann Phys Rehabil Med* 53(1):60-67.

## **Appendix One - Case Studies**

### **Case Study 1 – Class 1a dwelling – retrofit funded by MyAgedCare**

Our bathroom, cedar lined, took two carpenters to install rails. The first one wanted to go in from the room on the other side of the shower, but the second was able to do the work using a proper stud finder. We have had rails successfully installed at front and back doors as part of our Aged Care package, which is working well however.

Inclusion of railings at entry doors and in the bathroom give us added security against falls, particularly in the shower, having lost a friend to a fall in the shower. Falls result in a high percentage of admissions to nursing homes, ending many useful lives. The point of this exercise in making homes accessible is about the quality of life to which every person is entitled.

I fully support this move to make homes and buildings universally accessible. My only comments on the difference between Gold and Platinum are the essential needs for safety and accessibility in kitchens and bathrooms - has to be Gold all the way! I've watched a friend in a wheelchair getting hot dishes out of an oven onto her knee! Safety is essential in the kitchen around heat and flames.

Thinking further about this important issue, I'm reminded of Graeme J, building units at Rosebud, including one to be wheelchair accessible for himself. He made plans and his cousin took over the contract. In the end despite Graeme's supervision, bathroom doors opened the wrong way and on one occasion he was tipped out of his chair at the open front door by the door problem. Postie arrived with a parcel for him, handed it over to the prostrate Graeme "Here you are mate" and left. While this is funny, it is typical of attitudes to disability. Builders need to be closely supervised when making homes accessible or doing retrofits, or as happened to Graeme, they revert to standard ways.

Given the Federal Government's MyAgedCare commitment to provide packages to keep older people in their homes, the highest level of accessibility is essential in new builds to save the cost of retrofitting. My husband (82) and I have been fortunate to have two Level 2 packages that have provided some modifications to a house we chose for this period of our lives. Those modifications relate to railings for entry and bathroom handrails. The house has wide openings in the event either of us need a wheelchair so it makes sense that all new builds - hallways and doorways - are so designed. I use a mobility scooter, so consideration of storage, safe charging, and access for electric mobility devices is also necessary. There have been fires in hallways relating to scooter/chair charging.

New builds in our area are increasingly sited on tiny blocks limiting the space a scooter or wheelchair could move around outside or even allow modest recreational space for raised beds for gardening, which lifts spirits, providing basic opportunities for vegetable, herb growing.

We have been provided with adjustable beds which take up more room than our queen sized bed, needing more power points too, so bedrooms must be large enough to accommodate and move Hospital style beds.

Our kitchen has been designed to suit us both but I would not be able to cook in it if using a wheelchair - benches, stove etc too high of course. Laundry would also be impossible to access from a chair, hard enough using a crutch.

*For people with disabilities Independence is precious. A properly designed home makes that independence possible, less effort, meaning less likely to contribute to further deterioration and dependence on care.*

Fran Henke

48 Lyall Street

Hastings, Vic

### ***Case Study 2 - Class 1a dwelling – Unmet need because cannot afford to do retrofit, cannot get funding***

I've had polio since I was 11 months old and now that I'm in my late 60s I find it extremely challenging with the way houses are built and the lack of accessibility options for the future.

My current condition is due to polio, osteoporosis, 2 fractures in my left leg and general pain/weakness/fatigue due to post-polio syndrome – I am bound to a wheelchair in the house and scooter outdoors. My husband (aged 78) and I live in a modest 3 bedroom 2 bathroom single storey house.

The greatest challenge I face now is to have funding to build a Platform Lift to enable me to get to my car and drive out. This is because there are 3 steps down from the family room to get to the undercover pergola then garage. Numerous assessments and quotes put this into a TOO HARD BASKET: either use up the small backyard with landings and ramps or install a Platform Lift from the family room which both cost a fortune for which I cannot get funding when I need it most.

Had I known then what I know now in order to live independently in my house, I would have wanted to have my house built with:

- a) Larger doorways, ensuites, corridors, bedrooms. (NSL – large bedrooms not specified in Silver Level Options 1 or 2)
- b) Wide and accessible exit to the backyards
- c) Steps to comply with height rise standards to enable provision of ramps (NSL)
- d) Larger single garages to accommodate wheelchairs or scooters
- e) Internal entry from garage into house

- f) Larger laundry to accommodate side by side appliances plus drying and broom cabinet (NSL)
- g) Kitchens with adequate space and bench heights to suit all disabled equipment (NSL)
- h) As some of us cannot take the garbage & recyclable bins out for collection – a facility such as a sliding chute (channel or passage from kitchen to bins) taking rubbish directly to the garbage bins (NSL)

NOTE: NSL denotes not included in Silver Level

### **Case Study 3 – Class 2 dwelling - New build**

A flat, built in 2010, specifically for 'women over 65 years of age, who are in danger of becoming homeless, with a view to ageing-in-place' could have met the Silver Level requirements of the current *Livable Housing Design Guidelines*.

However, as can be seen, it was far from fit for the purpose for which it was built:

- a) Main entrance central opening doors too heavy to open from wheelchair. (NSL)
- b) Stepless entry from spacious corridor, with wide door that was so heavy that it challenged even a young, able-bodied person to open it. No hope of opening it if you were in a wheelchair (NSL)
- c) Ditto door from lobby to car park
- d) Ditto door to bin room, getting rubbish in to bin room and opening the lids on industrial size bins (NSL).
- e) The main entrance single door opening is way less than the Gold Level recommendation of 850cm and is now way too difficult for me to manage to open without having to use my whole body to push on it. A feat that is proving even more difficult trying to get my shopping jeep through. (NSL)
- f) Installation of an electric jug and microwave oven took up half the kitchen's available bench space (NSL)
- g) All kitchen cupboards were above/higher than the cooktop. The only other storage space in the flat was a built-in robe in the main bedroom. (NSL)
- h) One electric plug per room, close to the floor & inaccessible
- i) Step-in shower, with no lip, flooded the entire bathroom floor every time the tap was turned on. No towel, nor any other, rail (NSL)
- j) 2 very small bedrooms
- k) Small balcony, with a high lip to access (NSL)
- l) Flat was on 5<sup>th</sup> floor. Lift regularly went out, sometimes taking weeks to fix. (NSL)
- m) Water system, with loud grumbling noises and ghostly clanking of pipes, broke down on multiple occasions (NSL)
- n) One carpark and one storage cage that could not withstand burglary (NSL).

#### **Case Study 4 - Class 1a dwelling - self-funded retrofit.**

Liz's story

I have post polio syndrome and walk with crutches. I am anticipating a time when I will need to use my wheelchair, now for outside use, more inside the house. We recently made some modifications to our home. It is a 1910 home that had been previously renovated. This involved updating the kitchen, main bathroom and ensuite.

We used graded non slip floors, made one bathroom wheelchair accessible and made more space in the galley kitchen adding easy closing drawers, some more accessible cupboards and the oven was chosen with particular easy use features.

It is very difficult to bring an old house to an accessible standard. Even after recent modification our house does not meet any reasonable access standard although it is an improvement on how it was. For example the doorways to the front four original rooms are too narrow (74 cm width) for wheelchair access (NSL). Original rooms are small. There is a step to the front and back doors (NSL) and two to the small back garden from the verandah that require a larger remodelling to get rid of. It is not simple to put in a ramp as space is required to get the right gradient.

Another reason retrofitting houses is difficult is lining up funding with the project time lines. We chose not to seek funding through the NDIS because the process is too lengthy to fit in with a project where we were lining up builders who were available and at that same time lining up a house to stay while the work was being done.

We are fortunate that we are not reliant on the NDIS to do this work. For those that are, I hope that the system takes into account the reality of managing a home modification project.

#### **Case Study 5 - Class 1a dwelling (Government-owned Housing Commission) Accessibility mostly built in)**

When I got my housing commission house - government-owned - it was built brand new. And it was wheelchair-accessible, except the kitchen. But I got a lower bench, that I can use [IN A WHEELCHAIR]. I have been here for over 17 years and had no trouble with the house. My gardens were already done for me, too. And they fix anything if it breaks.

#### **Case Study 6 - Class 1a dwelling – Self-funded new build**

Five years ago I endeavoured to build two duplex wheelchair accessible homes.

I consulted with occupational therapists and specialist access building consultants during the design phase. The final working drawings signed off for contract met all wheelchair access needs. I was unaware that working drawings are nothing more than mud maps as far as engineers are concerned. I was not fully kept up to date with consultations between the builder and planner at council.

Post initial planning permit approval I was advised that the council required a lowering of the building height and this incurred an extra \$10,000 to redesign and rebuild the roof. I was not told that they were raising the floor!

I did not secure engineering plans until the building was at lock up stage and that was only after a lot of pressure.

When I first saw the slab, I was stunned to hear that the building had been raised supposedly due to changes by council regarding 100 year flood levels. We have only lived on the site for 25 years and have not had the opportunity to experience any obstruction to the street by water so far. We do live at the higher end of the street. The building slab is 450cm higher than the approved final working drawings, 650cm higher than the original and all neighbours' houses and 700cm above street level.

On completion 3 years later:

**Duplex One** almost made the grade. The building has a 'drive in drive out' lift, all doors 900cm opening with min of 1500mm turning space, a large wet bathroom with built in seat and wheelchair hand basin access, accessible bedrooms, kitchen, laundry and living areas.

The driveway is exceedingly steep with access to the front door difficult to manage for the frail and those using crutches. Wheelchair transfer to car is dangerous in the driveway and needs to take place in the street.

Some internal walls were moved by 300cm resulting in some areas of the internal space being difficult to negotiate in a wheelchair.

Extra costs were incurred fixing grab rails - even though during the build an OT spray painted studs with the builder present where extra battens were to be placed. The extra battens could not be located and it is assumed they were not fitted.

External access to the house is restrictive and incurred an extra \$28,000 in landscaping costs to enable wheelchair access to the front door and back yard.

**Duplex Two** failed in too many areas due to a lack of understanding of intent at council restricting the length of the building by 800cm. The rear yard of the duplex is twice the size of the one we retained and this affected negotiable space in some rooms of the house. A bit of a fiddle would enable a lift to be retro fitted.

The building could be made fully accessible with some retro modifications which was the suggestion of the builder.

I believed I was educated in the process of accessible housing and had worked with people who understood what was required. The reality however, I learnt, is that designers and well-meaning builders are not the ones in control of final plans and construction. Builders contract out everything from design, planning permits, construction to individuals who you may not

meet and they will not know of the needs of the person for whom the house is being built. Further to that city planners and council can be expected to have little real understanding of the needs an individual wheelchair user. Planning permits are issued as a process of compromise and planners at council work with the desires of the home builder and with their neighbours' objections.

Part of this process is the neighbour's planning meeting, I headed off to the council offices in my powerchair, a familiar sight for my neighbours. The allocated council meeting room had to be changed at the last minute, so I could attend the meeting. Two neighbours were understanding and two just did not want anything to change. Among one of the objections was the one the possible disturbance of the noise of a garage door being opened at night. As a distraction the council planner asked why a lift was being installed. The builder's contracted planner responded that the lift will only be used at most few times when his client accessed his bedroom and anticipating a complaint he added it will not be noisy. The fact that the house would be unusable for me without it and that lift is electric and is in the centre of a fully insulated accessible building was not mentioned. I am sure it never entered the contracted planner's mind to think why the houses were designed as fully accessible wheelchair homes.

I left that meeting with what I understood to be a negotiated permit that was not that different to the final working drawings that had been prepared with council planners over the previous 12 months. Alas, there were further meetings with the contracted planner, engineers and council that at the time I was not aware of, where changes took place such as raising the slab height by 450cm. The step down from my laundry door became 700cm and 1300cm from a side boundary fence, *try ramping that*. I had to build 4 rail extra high fences and after the handover I built retaining walls and raised the ground level by 450cm supported by permeable and conventional drainage and installed a step which provides exciting wheelchair access to the side of the house where I had intended to put an accessible clothes line...

### ***Case Study 7 – Class 1a dwelling – occasional self-funded modifications, over years***

In my case, and I'd say, for most of the others, we haven't had renovations done to these standards - only bits and pieces done over the years that are the most convenient and least costly options for older houses.

## **Case Study 8 – Builder with a dream of universal accessibility**

**Townsville builder's dream for disability-friendly housing to become standard, 9 Dec 2018**

<https://www.abc.net.au/news/2018-09-12/accessible-housing-push-in-townsville-for-inclusive-living/10209796>

North Queensland builder Martin Locke has been pushing for Townsville to become a pilot city where all new homes are built to a silver level standard, to meet the needs of Australia's growing populations of older people and people with a disability.

Mr Locke has garnered support from Townsville City Council, land developers and the building industry, but without a financial incentive provided by Government he said there is no way every new home buyer will build to that standard.

"It is a bit sad that we have to offer financial incentive for something that is just and right ... but unfortunately it is just not happening," Mr Locke said.

"Making it mandatory isn't the way to go, but I think everyone will realise where you can you should build to this standard.

"It future-proofs the homes you are building for the fastest growing market, the aged and the disabled."

### **Liveable housing to meet population needs**

In 2010 the Federal Government's Liveable Housing Australia Guidelines were developed to address the shortage of homes that meet Australia's growing populations needs.

The Guidelines' target was for all new homes to be built to silver level standard by 2020.

Silver level is the minimum level needed for a person with a wheelchair to be able to live in a house.

The Queenslanders With a Disability Network (QDN) has estimated that less than 5 per cent of new homes are being built to that standard.

"There have been lots of targets set, but without actual commitment and requirements put in place and incentives to get the building industry to reach those targets," Michelle Moss from QDN said. "So the project here in Townsville, which is about silver level housing, is actually helping support meeting those targets."

Mr Locke said the few changes needed to make a house silver-level compliant add less than \$2,500 to the cost of a new home.

The main changes include having one metre-wide hallways, a step-free shower, 870 millimetre-wide doorways, extra beams in the walls of the bathroom to allow for grab rails to be installed, one entry without stairs and 1.2m between the toilet and the toilet door.

"The thing about silver level housing is it is so basic, it is so easy to do it at the start of construction," Mr Locke said.

"There have been numbers saying it costs 20 times more to do it retrofitting."

### **Rental market not wheelchair friendly**

Townsville resident Jeff Wright was badly injured while riding his motorbike in 2015 and now requires a wheelchair for mobility.

Mr Wright spent four months last year looking for a rental property that he could access in his wheelchair. Confounded by the rental options available, Mr Wright ended up having to buy a property and modify it to make it wheelchair accessible.

"I was in the building game before the accident so I had a good idea of what I wanted to do. But still, it took six months and I was in a hotel for six months waiting for the modifications to occur."

### **Even after \$130,000 of modifications Mr Wright said his home is not ideal.**

"A couple of the doors have to be lined up perfectly or I'll skin my knuckles," he said.

Queenslanders With a Disability Network has reported that 830,000 Queenslanders with a disability are facing a housing affordability crisis. Ms Moss said people with a disability and older people on a pension find it particularly hard to find housing that is both suitable and affordable.

"Often people are on fixed incomes, which impacts on their ability to participate in the housing market and then there is a lack of options," she said.

Mark Henley from the Queensland Council of Social Services (QCOSS) said this lack of accessible housing is preventing people with a disability from integrating wholly into society.

"If you don't have that foundational piece around housing, other areas will suffer," Mr Henley said.

"Housing is foundational as far as people having good health, opportunities for kids to get to school and be educated ... accessing employment and sustaining employment."

### **Accessible homes support whole community**

Liveable Housing Australia has reported a 60 per cent chance that a home will be occupied by a person with a disability at some point.

As Australia's population ages, accessibility is also on the minds of many older home buyers.

Mr Henley said it is not enough to have accessible homes just for people with disabilities.

"People with a disability want to actually go and visit family and friends and also get access to the other infrastructure that exists whether it is retail or commercial," Mr Henley said.

"The more they can access other premises the more inclusive the whole community is."

Mr Wright said he has to be a "bit inventive" when it comes to accessing some houses or businesses.

"There are some places that I just cant get into," he said.

"The boys will lift you up and carry you, but it is not quite dignified either and you don't want to impose on your mates," he said.

"You want to feel independent rather than feel obligated on people's assistance."

### **Subsidy program proposal**

Ultimately, Mr Locke said he would like to see a First Home Buyers Grant-style subsidy scheme for silver level housing established, but for the time being he would be happy to see a 12 month pilot program in Townsville.

Mr Locke said both State and Federal Government representatives have been very enthusiastic during meetings about the Townsville pilot but he fears the project has stalled around the subsidy.

"We have done everything we can as a local community," Mr Locke said.

"I am hoping that State and Federal Governments really do find a way to match what the Townsville community has done, that is the final piece of the puzzle."