Supported Independent Living Commissioning Approach

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What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Three times as many women have MS than men. Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

George Pampacos
President

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SIL Commissioning Consultation

Executive Summary

MS Australia welcomes the opportunity to respond to the Supported Independent Living (SIL) Commissioning Consultation. SIL plays a critical role in enabling people with disability, including people living with multiple sclerosis (MS) and other progressive neurological conditions, to live safely, meaningfully and with dignity in homes of their choosing. MS Australia supports the intent of improving the quality, safety, reliability and sustainability of SIL, but considers that commissioning should be used selectively where existing planning, pricing, regulatory or market stewardship arrangements are not adequately meeting participant needs.

Future commissioning arrangements must recognise the diversity of SIL participants, living arrangements and support needs. For participants with MS and other progressive or fluctuating neurological conditions, quality is not only about increasing independence; it may also mean maintaining function, preventing avoidable deterioration, delaying hospitalisation, avoiding premature entry into residential aged care and supporting continuity, wellbeing and choice over time.

SIL Commissioning should focus on meaningful participant outcomes, specialist capability, workforce stability, proactive safeguards, supported decision-making, innovation that improves lives, and provider sustainability. It should strengthen, not reduce, participant choice and control by sustaining diverse, specialist, local and culturally safe providers, funding flexible support models, and recognising the true cost of quality support.

MS Australia recommends that any SIL commissioning model is targeted, rights-based, adequately funded, co-designed with participants and families, and measured by whether people can continue to live safely and meaningfully in homes and communities of their choosing.

Lived Experience

This submission draws on the experiences and expertise of MS Australia's our state and territory Member Organisations. Our Member Organisations are registered NDIS providers who provide supports to people living with MS and other neurological conditions. They are experienced in delivering specialised neurological SIL services that focus on whole-of-person support and supporting people to continue living safely and meaningfully in their chosen home.

MS Australia Recommendations

- SIL commissioning is targeted to SIL participants and service settings where current planning, pricing, market or regulatory arrangements may not reliably deliver safe, stable and clinically appropriate supports.
- SIL commissioning frameworks measure and fund quality through meaningful participant outcomes, workforce capability, safeguarding, continuity of support, specialist expertise and the ability of providers to respond as people's needs change over time.
- SIL commissioning frameworks should require and fund proactive, rights-based safeguards that protect participant safety, health, wellbeing and autonomy across shared, individual and specialist living arrangements.
- SIL commissioning frameworks should fund and reward participant-centred innovation that improves outcomes, strengthens specialist capability and integrates disability, health and housing supports without reducing choice, safety or quality.

- SIL commissioning frameworks should enhance participant choice and control by sustaining diverse, specialist and local providers, funding flexible support models, and ensuring participants can make meaningful decisions about where and how they live.
- SIL commissioning frameworks should ensure provider sustainability by funding the true cost of quality, safeguarding, workforce capability, specialist expertise and service continuity across diverse provider types and markets.

Existing SIL Arrangements

The SIL population is increasingly diverse and includes people living in shared homes, Specialist Disability Accommodation (SDA), legacy group home environments and individual homes. It also includes participants with very different disabilities, support needs, health requirements, communication methods, decision-making support requirements and life goals. The sector now supports people who previously lived in institutions, younger people at risk of residential aged care, people with psychosocial disability and people transitioning from health or justice settings.

Importantly, SIL should not be treated as a single service model. The risks, outcomes and safeguards required for a participant living in a traditional shared home differ significantly from those of a participant living in a contemporary SDA arrangement or receiving individualised SIL support in their own home. Future commissioning must recognise this diversity and avoid creating a uniform solution for a highly variable participant cohort.

Question 1 (Participants): Which SIL participants could benefit most from additional government oversight of planning, delivering and monitoring of SIL supports?

Additional government oversight should be targeted to SIL participants and service settings where current planning, pricing, market or regulatory arrangements may not reliably deliver safe, stable and clinically appropriate supports. Oversight should be prioritised for the following groups of participants:

- **Participants with progressive or degenerative conditions:** people with MS and other progressive or fluctuating neurological conditions who need regular clinical oversight, multidisciplinary review and proactive monitoring as their support needs change over time.
- **Participants with complex or changing support needs:** people with complex health, neurological, cognitive, behavioural, communication or psychosocial needs; increasing functional decline; high-intensity or continuous support requirements; or reliance on multiple systems including disability, health, housing, hospital, mental health or aged care.
- **Participants at risk of crisis or service breakdown:** people at risk of avoidable health deterioration, hospitalisation, homelessness, provider withdrawal, failed placements, service instability or premature entry into residential aged care.
- **Participants who may be unheard or unable to raise concerns:** people with complex communication needs, cognitive impairment, acquired brain injury, dementia, limited advocacy, no active family or informal safeguards, or difficulty identifying and reporting poor-quality supports.
- **Participants subject to restrictive or provider-controlled arrangements:** people subject to restrictive practices or highly structured supports, or living where the provider controls housing, household routines or multiple supports, creating possible conflicts of interest.
- **Participants in shared or group living settings:** people whose wellbeing is affected by shared staffing, participant compatibility, household routines, vacancy pressures, participant-to-participant risk and continuity of support.

- **Participants in individual SIL arrangements:** people living alone who may face social isolation, fewer natural safeguards, reduced visibility of health deterioration, reliance on stable staffing and workforce shortages affecting daily support.

- **Participants in thin or specialist markets**: people in rural, regional or remote areas; people needing specialist neurological, behavioural, cultural or clinical capability; First Nations participants; culturally and linguistically diverse participants; and participants whose needs are uncommon, highly specialised or difficult for the market to sustain.

MS Australia recommends SIL commissioning frameworks are targeted to SIL participants and service settings where current planning, pricing, market or regulatory arrangements may not reliably deliver safe, stable and clinically appropriate supports.

Question 2 (Quality): What do high-quality SIL supports look like?

High-quality SIL supports enable people with disability to live safely, meaningfully and with dignity in homes of their choosing. Quality should not be measured only by roster coverage, task completion or the absence of reportable incidents. It should be assessed through participant outcomes, lived experience, continuity of support, safeguarding practices, workforce capability, and the provider's ability to respond as needs change.

High-quality SIL is person-centred. It promotes choice and control over daily routines, living arrangements, support workers and life decisions, while respecting each participant's goals, preferences, culture, communication style and identity. It should maintain and build skills wherever possible, support dignity of risk, strengthen independence, and enable social connection, community participation, recreation, education, volunteering or employment where appropriate.

For participants with MS and other progressive or complex neurological conditions, quality also means recognising maintenance, stability and prevention of decline as important outcomes. Supports should identify functional change early, monitor health, wellbeing, fatigue, mobility and cognition, and implement allied health recommendations, assistive technology and communication supports consistently. Individual support plans should be reviewed regularly and adapted as needs change.

A skilled and stable workforce is central to quality. Staff should understand the participant's disability and support requirements and have condition-specific capability in areas such as fatigue management, cognition, communication changes, mobility decline, falls prevention, swallowing difficulties, assistive technology, ageing with disability and health system navigation. Providers should work collaboratively with participants, families, support coordinators, nursing staff, allied health professionals and health services to deliver coordinated, responsive care.

A commissioning framework should recognise specialist providers and avoid using organisational size as a proxy for quality. It should support both shared and individualised models, ensuring shared arrangements still preserve privacy, personal choice, individual planning and access to individualised support. Participants and families also need accessible information about provider capability, workforce experience, support models, specialist expertise, complaints handling, risk management, participant outcomes and regulatory findings.

A commissioning framework should measure quality through meaningful outcomes, including participant experience, workforce competence, continuity of support, safeguarding, culturally safe practice, health outcomes, supported decision-making and continuous improvement. Any enhanced expectations must be funded, including supervision, practice leadership, clinical escalation pathways, quality systems, data capability, participant engagement, workforce development and specialist neurological capability where required.

MS Australia recommends that SIL commissioning frameworks measure and fund quality through meaningful participant outcomes, workforce capability, safeguarding, continuity of support, specialist expertise and the ability of providers to respond as people's needs change over time.

Question 3 (Safeguards): How should SIL supports protect the safety, health, wellbeing and rights of participants?

Safeguarding in SIL must be rights-based, preventative and embedded in everyday support practice. It should protect participants from abuse, neglect, exploitation, violence and coercion while also upholding their autonomy, privacy, dignity, relationships, cultural identity, choice and control. Effective safeguards should not focus only on compliance, incident reporting or responding after harm has occurred. They should identify risks early, support informed decision-making and enable participants to live ordinary lives with appropriate dignity of risk.

Core safeguards should include individualised risk assessment and support planning, supported decision-making, accessible information about participant rights, independent advocacy, health and emergency plans, clear complaints and escalation pathways, restrictive practice oversight where relevant, and continuity planning for workforce shortages, provider exits and emergencies. Participants, families, carers, advocates and workers must have safe, accessible and culturally appropriate ways to raise concerns without fear of retaliation or loss of support.

Safeguards must also reflect different living environments. Shared homes require active oversight of participant compatibility, shared staffing, household routines, privacy, vacancy management and participant-to-participant risks. Participants living alone may need regular wellbeing reviews, independent check-ins and proactive monitoring because risks such as social isolation, workforce disruption and health deterioration may be less visible. Contemporary SDA and specialist settings should be assessed on support quality, participant outcomes, workforce capability and continuity, rather than assuming the housing model itself determines risk.

For participants with MS and other progressive or fluctuating neurological conditions, safeguarding must include proactive health oversight. Providers need capability to recognise and respond to participant's changes in mobility, fatigue, cognition, communication, swallowing, continence and general health; coordinate with allied health and medical professionals; support hospital admission and discharge; and adapt supports before deterioration leads to crises, incidents, carer breakdown or loss of housing stability.

A commissioning framework could strengthen SIL safeguards through enhanced monitoring of high-risk environments, independent participant wellbeing reviews, minimum workforce competency requirements, specialist capability standards, provider-of-last-resort arrangements, transparent quality reporting and obligations linked to participant outcomes. However, these requirements must be properly funded, as providers already undertake essential safeguarding work that extends beyond direct support, including risk management, emergency response, health coordination, restrictive practice management, participant engagement and complex decision-making support.

MS Australia recommends SIL commissioning frameworks should require and fund proactive, rights-based safeguards that protect participant safety, health, wellbeing and autonomy across shared, individual and specialist living arrangements.

Question 4 (Innovation): How can innovation by SIL providers enhance the quality of SIL supports and outcomes for SIL participants?

Innovation in SIL should improve participant outcomes, not simply introduce technology or reduce service costs. For our Member Organisations, meaningful innovation means more responsive, integrated and person-centred supports that improve quality of life, strengthen choice and control, support health and wellbeing, maintain function where possible, and enable people to remain safely in homes and communities of their choosing.

For people with MS and other progressive or fluctuating neurological conditions, innovation often means earlier identification of changing needs, better coordination across disability, health, housing, rehabilitation, SDA, respite and hospital systems, and flexible support models that can scale up as needs increase. This can help prevent deterioration, avoid hospitalisation, reduce carer strain, delay or prevent entry into residential aged care, and support people to maintain

independence and community connection. Examples include specialist neurological support models, integrated multidisciplinary planning, virtual clinical reviews, telehealth, assistive technology, smart home systems, digital care planning, remote monitoring where clinically appropriate, improved handover and rostering tools, mobile specialist teams, and stronger hospital discharge and housing pathways. Technology should enhance participant independence, communication, privacy, safety and continuity, but only with participant consent, privacy protections and human rights safeguards.

Workforce innovation should focus on capability, quality and flexibility rather than reduced staffing. This may include advanced support worker roles, specialist neurological teams, practice leadership, mentoring, joint disability and health training, structured career pathways and regional outreach models. Commissioning frameworks should support pilot programs, demonstration projects, co-design with participants and families, partnerships between specialist and mainstream providers, and access to innovation funding for providers of different sizes.

Innovation should ultimately be measured by whether it improves participants' lives, including autonomy, decision-making, wellbeing, continuity, community participation, social connection, workforce capability, transitions between systems and participant experience. A commissioning approach should create space for diverse, evidence-informed models of support and reward demonstrable outcomes rather than prescribing a single model or purchasing hours alone.

MS Australia recommends future SIL commissioning frameworks should fund and reward participant-centred innovation that improves outcomes, strengthens specialist capability and integrates disability, health and housing supports without reducing choice, safety or quality.

Question 5 (Participant choice): How can effective participant choice and control be enhanced, including in regions with smaller populations?

Participant choice and control must remain central to any future SIL commissioning model. Genuine choice is not simply selecting from a provider panel; it means participants have practical influence over where they live, who they live with, who supports them, how daily routines operate, how risks are managed and what outcomes matter most to them.

Participants should be able to choose between shared and individualised living arrangements, including in SDA, shared accommodation and individual homes. In shared homes, participants should still have meaningful control over housemates, personal routines, meals, visitors, cultural practices, community participation and support workers where possible. Compatibility processes should be transparent and participant-centred, and shared living should never be assumed because it is administratively easier or cheaper.

For people with MS and other progressive or fluctuating neurological conditions, choice also includes continuity. Participants should be able to remain in familiar environments, keep trusted support relationships, access specialist expertise as needs change and avoid unnecessary transitions that may worsen health, function or wellbeing. Choice and control should not be reduced because a person has complex communication, cognitive or decision-making needs. Instead, supported decision-making, communication supports, advocacy, trusted supporters and specialist advice should be strengthened.

In rural, regional, remote and specialist markets, choice can be limited by workforce shortages, housing shortages, specialised support needs or too few providers. Commissioning should respond by investing in specialist provider capability, regional workforce development, mobile and outreach models, virtual supports where appropriate, stronger housing pathways, and partnerships between local and specialist providers. It should also preserve provider diversity, including specialist, community-based, culturally safe, First Nations-led and culturally and linguistically diverse services.

Commissioning frameworks could strengthen choice if it improves service availability, sustains quality providers, enables specialist providers to participate, funds multiple support models, provides accessible information about provider capability and performance, and focuses on participant outcomes rather than prescribing one model. However, it could reduce choice if it limits

participation to a small number of large providers, restricts flexibility, reduces access to specialist services, creates barriers to changing provider or weakens smaller and local organisations. Success should be measured by whether participants have realistic access to high-quality, culturally safe and person-centred supports that enable them to live safely and meaningfully in homes of their choosing.

MS Australia recommends future SIL commissioning frameworks should enhance participant choice and control by sustaining diverse, specialist and local providers, funding flexible support models, and ensuring participants can make meaningful decisions about where and how they live.

Question 6 (Provider sustainability): What's needed to ensure that SIL providers are sustainable?

Provider sustainability should be treated as a participant outcome issue. Participants cannot experience safety, continuity, choice or quality if SIL providers cannot maintain viable, skilled and responsive services over time. Future commissioning framework arrangements must therefore recognise that provider sustainability is not separate from participant wellbeing, but a necessary condition for stable and high-quality supports.

Sustainable SIL requires pricing and funding models that reflect the true cost of delivering safe, high-quality support. This includes direct support, supervision, practice leadership, workforce training, safeguarding, quality and compliance requirements, administration, coordination, emergency planning, technology, participant engagement and supported decision-making. Current pricing does not consistently recognise these essential functions, particularly for providers supporting people with complex or changing needs.

For our Member Organisations, sustainability also depends on recognising the additional capability required to support people with MS, other progressive neurological conditions and complex disabilities. Providers need capacity for neurological practice leadership, health and allied health coordination, hospital liaison and discharge planning, SDA and housing pathway support, assistive technology, family engagement, workforce supervision and flexible responses as participant needs change.

A sustainable SIL sector also requires a stable and capable workforce. Providers must be able to recruit and retain workers, provide ongoing training, fund supervision and mentoring, build specialist capability, support workforce wellbeing and maintain safe staffing levels. Workforce shortages, turnover and casualisation place pressure on continuity and quality, especially in specialist and regional markets.

Commissioning frameworks should address vacancy and occupancy risk, particularly in shared living, rural and remote areas and specialist markets where participant matching takes time and support costs continue during vacancies. It should preserve provider diversity, including smaller, specialist, local, community-controlled, culturally specific and neurological providers, rather than favouring scale over capability. Funding certainty, appropriate indexation, flexibility, reduced duplication and consistent compliance expectations are also essential.

Commissioning frameworks can strengthen sustainability if it funds quality, safeguarding, workforce development, specialist expertise and continuity of support. However, it could undermine sustainability if it favours large providers, excludes smaller organisations, creates unfunded compliance burdens, imposes rigid models or creates a two-tier market. The ultimate test should be whether participants continue to have access to stable, skilled and responsive supports that enable them to live safely and meaningfully in homes of their choosing.

MS Australia recommends future SIL commissioning frameworks should ensure provider sustainability by funding the true cost of quality, safeguarding, workforce capability, specialist expertise and service continuity across diverse provider types and markets.

Conclusion

MS Australia supports the intent to improve the quality, safety and sustainability of SIL, but recommends that commissioning frameworks be targeted, rights-based and designed around participant outcomes. Any future model should strengthen, not limit, choice and control by sustaining diverse, specialist and local providers, funding flexible and innovative supports, embedding proactive safeguards, recognising workforce and specialist capability, and covering the true cost of quality service delivery. Above all, SIL commissioning frameworks should be measured by whether participants, including people with MS and other progressive neurological conditions, can continue to live safely, meaningfully and with dignity in homes and communities of their choosing.

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