FIGHT PARKINSON"S PUBLIC SUBMISSION TO THE CONSULTATION ON THE NEW INDIVIDUAL DISABILITY ADVOCACY PROGRAM (IDAP) - JANUARY 2026

ABOUT FIGHT PARKINSON'S (FP)

Fight Parkinson's is a leading Australian not-for-profit organisation supporting people living with Parkinson's and rarer Atypical Parkinson's conditions, including Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), and Corticobasal Syndrome (CBS).

FP works across the continuum of Parkinson's, from diagnosis through to advanced disease and palliative care, supporting individuals, families and carers through education, service navigation, multidisciplinary health support, advocacy, research translation, and community connection.
As a condition-specific organisation, FP brings deep clinical, system and lived-experience expertise to support people with progressive neurological conditions. These conditions are complex, lifelong, and characterised by changing and intersecting health, disability, and aged care needs that are often poorly understood within mainstream systems.

Fight Parkinson's Services and Role in Individual Advocacy

While Fight Parkinson's is not funded as an independent disability advocacy organisation, in practice FP provides substantial supported self-advocacy, system navigation and rights-based education, particularly for people who are already overwhelmed by fragmented systems and the daily impacts of a progressive neurological condition.
This includes:

- Supporting people to understand and navigate complex systems such as the NDIS, My Aged Care, primary care, public hospitals, and private health services
- Providing scripts and practical tools to support self-advocacy, for example to ensure timely access to Parkinson's medications in hospital
- Assisting people to understand NDIS eligibility, applications, appeals, reviews, and plan changes
- Supporting advocacy in My Aged Care referrals, assessments, and ongoing care management
- Assisting people to identify gaps in multidisciplinary care and connect with appropriate supports, including allied health, mental health, carer support, continence advice, specialist services, and palliative care
- Delivering education through programs, booklets, fact sheets, and expert-led sessions that build confidence, knowledge, and self-advocacy
- Supporting people to raise concerns about health and aged care services by educating on rights and responsibilities and providing guidance on internal and external complaints pathways (eg the NDIA funded - Your Care Your Choice program)
- Referring people to formal advocacy services and complaints bodies where independent representation or escalation is required.

FP's experience reflects the reality that individual advocacy often occurs along a continuum, with early, preventative, and supported self-advocacy playing a critical role alongside formal, independent advocacy services.

RESPONSE TO CONSULTATION QUESTIONS

QUESTION 1

AFTER READING THE "WHAT WE'VE HEARD SO FAR" SECTION OF THE CONSULTATION PAPER, DO YOU THINK IT SOUNDS RIGHT? PLEASE COMMENT (OPTIONAL).

RESPONSE:

Yes, overall "What we've heard so far" reflects the experiences of people with Parkinson's. The section accurately captures the critical role that individual disability advocacy plays as a safeguard, supporting people with disability to access trusted information, build skills, uphold their rights, and participate in their communities—particularly where there is risk of harm, discrimination, or system failure.
We strongly agree with the emphasis on advocacy being valued, preventative as well as responsive, available face-to-face, culturally safe, disability-driven, and delivered by stable organisations with a long-term presence.

From our experience supporting people living with Parkinson's and rarer Atypical Parkinson's conditions (including Progressive Supranuclear Palsy, Multiple System Atrophy, and Corticobasal Syndrome), we also agree that advocacy is needed for many reasons and across long, progressive disease trajectories rather than at a single point of crisis.

Importantly, people with lived experience of these conditions are often already overwhelmed by the complexity of systems, multiple points of access, and the day-to-day management of a progressive neurological condition. Effective care typically relies on a multidisciplinary health response, which is frequently pieced together across the NDIS, My Aged Care, primary care, public hospital services, and private health providers.

The fragmented nature of these systems means that, in practice, trusted condition-specific organisations such as Fight Parkinson's are frequently required to help people understand, navigate, and coordinate across multiple service and funding environments—often before formal advocacy is accessed.
We also support the recognition in the paper that:

- not everyone has informal supports available
- some people require specialised knowledge or skills to be effectively supported
- current advocacy funding does not meet demand
- improved data is needed to understand unmet needs and inform policy.

One area that could be strengthened is clearer recognition that individual advocacy already occurs across a broader ecosystem of support, including through supported self-advocacy, system navigation, education, and referral delivered by trusted community-based and condition-specific organisations.
In practice, this includes helping people to:

- navigate complex systems such as the NDIS, My Aged Care, health and aged care services
- understand rights and responsibilities
- identify gaps in multidisciplinary support
- raise concerns or complaints through appropriate internal and external mechanisms
- access specialist advocacy services when independent representation or escalation is required.

These activities strongly align with the principles outlined in “What we’ve heard so far”, particularly around skill-building, safeguards, access, and inclusion. Explicitly recognising this continuum of advocacy support will strengthen the design and effectiveness of the new program—especially for people living with complex, progressive and less well-understood neurological conditions.

QUESTION 2

TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE AIMS IN THE “OUR PLAN FOR A NEW PROGRAM” SECTION OF THE CONSULTATION PAPER? PLEASE COMMENT.

RESPONSE:

We strongly agree with the aims set out in “Our plan for a new program”. The proposed goal and objectives provide a clear, rights-based foundation for individual disability advocacy and reflect well what we know is required to support people with disability—particularly those at greatest risk of harm—to make their own choices and stand up for their rights.

We support the program’s focus on:

- prioritising people most at risk of harm
- ensuring timely access to individual disability advocacy
- strengthening culturally safe advocacy
- building the capability of advocacy organisations to deliver high-quality, inclusive, and responsive support
- addressing discrimination, systemic barriers, and opportunities to improve policy and practice.

These aims are well aligned with the findings of the Disability Royal Commission and reflect the realities faced by people navigating complex and often fragmented systems.

From our experience supporting people living with Parkinson’s and rarer Atypical Parkinson’s conditions (including Progressive Supranuclear Palsy, Multiple System Atrophy, and Corticobasal Syndrome), we particularly support the emphasis on access “when it is needed”. For people living with progressive neurological conditions, advocacy needs frequently arise at multiple points over time, as health, functional capacity, and support needs change.

The strength of the plan lies in its recognition that effective advocacy is not limited to crisis response, but includes early intervention, skill-building, and support to navigate complex systems such as the NDIS, My Aged Care, primary care, and public and private health services. These systems are often pieced together by individuals and families who are already managing the significant daily impacts of a progressive condition.

One area where the aims could be strengthened is by more explicitly recognising the role of trusted, condition-specific, and community-based organisations within the broader advocacy ecosystem. In practice, these organisations often provide critical supported self-advocacy, education, system navigation, and referral into formal advocacy services. Recognising and connecting these roles within the program design would strengthen continuity, accessibility, and early support—particularly for people with complex, less well-understood conditions.

Overall, we agree strongly with the direction and intent of the aims. With explicit recognition of the continuum of advocacy support and the role of condition-specific expertise, the new program has the potential to deliver meaningful, preventative and sustainable advocacy outcomes for people with disability.

QUESTION 3

TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE LIST OF ACTIVITIES WE HAVE IDENTIFIED TO ACHIEVE THESE AIMS? PLEASE COMMENT.

RESPONSE:

We strongly agree with the list of activities identified to achieve the aims of the new program. Collectively, these activities reflect a comprehensive and well-considered approach to strengthening individual disability advocacy across Australia and align closely with what is required in practice to support people with disability—particularly those facing complex, intersecting, and evolving needs.

We particularly support the focus on:

- funding a diverse, nationwide network of independent advocacy organisations, including access for people in regional, rural, and remote communities
- targeted outreach to people facing intersecting inequalities and heightened risk of harm
- training and professional development for advocates
- building strong relationships between the department and funded organisations
- collecting and using data to understand access, outcomes, and unmet demand.

These activities align well with the Disability Royal Commission's findings and reflect the reality that advocacy must be accessible, skilled, culturally safe, and sustainable over time.

From our experience supporting people living with Parkinson's and rarer Atypical Parkinson's conditions (including Progressive Supranuclear Palsy, Multiple System Atrophy, and Corticobasal Syndrome), we strongly support the emphasis on reaching people with intersecting needs and those who may be isolated, living in segregated settings, or experiencing rapid changes in health and functional capacity.

People living with progressive neurological conditions often rely on a multidisciplinary response that is fragmented across the NDIS, My Aged Care, primary care, public hospitals and private health providers. In this context, advocacy demand frequently arises not only in moments of acute risk, but through ongoing system navigation, care coordination challenges, and changes in eligibility, funding, or service access.

Again, the activities could be strengthened is by more explicitly recognising and supporting linkages between funded advocacy organisations and trusted, condition-specific and community-based organisations. In practice, organisations like FP often provide early identification of need, supported self-advocacy, education, and referral into formal advocacy pathways. Strengthening these connections would improve reach, early intervention and continuity, and reduce the likelihood of people only accessing advocacy at crisis points.

We also strongly support the proposed emphasis on data collection and evaluation, noting the importance of capturing:

- unmet demand
- repeat or longitudinal advocacy needs
- complexity and duration of advocacy required for progressive conditions
- system-level barriers that drive repeated advocacy needs.

Overall, we agree that the proposed activities provide a strong foundation to deliver the program's aims. With explicit recognition of the broader advocacy ecosystem and the role of trusted condition-specific organisations in enabling access and early support, these activities have the potential to deliver meaningful, preventative, and sustainable advocacy outcomes for people with disability.

QUESTION 4
AFTER READING THE "OUR PLAN FOR A NEW PROGRAM" SECTION OF THE CONSULTATION PAPER, DO YOU THINK THE OVERALL PLAN WOULD WORK? PLEASE COMMENT (OPTIONAL).

RESPONSE:

Overall, we believe the proposed plan provides a strong and workable foundation for strengthening individual disability advocacy in Australia. The intent of the plan aligns with the findings of the Disability Royal Commission and reflects what people with disability consistently tell us they need: timely access to advocacy, trusted and skilled advocates, and systems that are easier to understand and navigate.

From the perspective of people living with Parkinson's and rarer Atypical Parkinson's conditions, the plan's emphasis on stability, continuity, and capability is particularly important. Advocacy needs for people with progressive neurological conditions rarely occur once or at a single point in time. Instead, advocacy needs arise repeatedly over the course of the condition as symptoms change, functional capacity fluctuates, care arrangements shift, and people move between health, disability, and aged care systems.

The plan is most likely to work well where it enables advocacy to function not only as a response to crisis, but also as a preventative safeguard. Early access to advocacy—before harm escalates or people disengage from systems—can reduce distress, prevent avoidable deterioration, and support people to maintain choice and control over their lives.

We strongly support the potential for the plan to enable a "no wrong door" approach. For people living with Parkinson's, who often engage simultaneously with health services, disability supports or aged care systems, it is neither reasonable nor realistic to expect individuals to determine which advocacy pathway applies before seeking help. Clear referral pathways, warm handovers, and shared responsibility between advocacy services will be essential to ensuring the plan works in practice.
With careful implementation that prioritises collaboration with trusted, condition-specific and community-based organisations, we believe the overall plan would work and represents a significant improvement on current arrangements.

QUESTION 5

TO WHAT EXTENT DO YOU AGREE OR DISAGREE THAT THE THREE GRANT PATHWAYS WOULD TOGETHER SUPPORT ACHIEVEMENT OF THE OBJECTIVES FOR THE NEW PROGRAM ARTICULATED IN THE CONSULTATION PAPER? PLEASE COMMENT.

RESPONSE:

We agree that the three proposed grant pathways, when implemented together and effectively coordinated, would support achievement of the objectives for the new program.
For clarity for the community, the three pathways are:

- a Service Delivery Stream, funding organisations to provide local, place-based, and face-to-face individual advocacy
- a National Advocacy Helpline Stream, providing short-term, phone-based advocacy, and triage
- a Sector Strengthening Stream, supporting workforce development, training, data use, and systemic advocacy.

Together, these pathways reflect how people actually seek and use advocacy support. Many people begin by seeking information or short-term assistance, often during a period of uncertainty or emerging concern. Over time, and as issues become more complex, they may require more intensive, local, or ongoing advocacy support.

For people living with Parkinson's and rarer Atypical Parkinson's conditions, this layered approach is particularly important. Advocacy needs may arise in different contexts, including hospital admissions, access to disability supports, transitions into aged care, changes in care needs, or when raising concerns about service quality, safety, or rights.

When well integrated, the three pathways have the potential to improve access through multiple entry points, reduce delays in receiving appropriate advocacy support, ensure people can move smoothly between short-term and longer-term advocacy, and strengthen consistency and quality across the advocacy sector.

The success of this approach will depend on strong coordination between pathways, including clear referral protocols and shared understanding of roles. With these safeguards in place, we agree that the three grant pathways together can meaningfully support achievement of the program's objectives.

QUESTION 6

TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE DETAILS OF THE PROPOSED SERVICE DELIVERY STREAM? PLEASE COMMENT.

RESPONSE:

We largely agree with the details of the proposed Service Delivery stream and strongly support its emphasis on longer funding periods, organisational stability, outreach, and network-based delivery.
For people living with Parkinson's and rarer Atypical Parkinson's conditions, trust and continuity are essential. Advocacy relationships are often built over time, particularly where conditions are progressive and needs evolve. Longer funding periods will support advocacy organisations to retain skilled advocates, invest in workforce development, and build sustained relationships with the communities they serve.

We also support the focus on outreach to people facing intersecting vulnerabilities, including those living in regional, rural, and remote areas, people experiencing cognitive change, people without informal supports, and those navigating multiple service systems at once.

The proposed emphasis on networks and collaboration is particularly important. People with Parkinson's often engage with trusted condition-specific organisations early, before formal advocacy services are accessed. Strengthening linkages between funded advocacy organisations and trusted community-based and condition-specific organisations would improve early identification of need, referral pathways, and continuity of support.

Overall, the proposed Service Delivery stream reflects the realities of supporting people with complex, progressive conditions and provides a strong foundation for sustainable, high-quality advocacy.

QUESTION 7

TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE DETAILS OF THE PROPOSED NATIONAL ADVOCACY HELPLINE STREAM? PLEASE COMMENT.

RESPONSE:

We generally agree with the proposed National Advocacy Helpline stream and support its role as a national entry point for short-term advocacy, information and triage.

For many people living with Parkinson's, a helpline can be an accessible first step, particularly at times of uncertainty, emerging concern, or when immediate guidance is needed. This is especially important for people in regional and remote areas, or for those who are unsure where to turn.

To be effective, the helpline must be well integrated with local advocacy services and aged care advocacy services. Clear referral pathways and warm handovers will be critical to ensuring people are not left with information alone when they require more intensive or ongoing support.

With these safeguards in place, we believe the National Advocacy Helpline can play an important role in improving access, supporting early intervention, and reducing escalation to crisis.

QUESTION 8

TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE DETAILS OF THE PROPOSED SECTOR STRENGTHENING STREAM? PLEASE COMMENT.

RESPONSE:

We agree with the proposed Sector Strengthening stream and see this as a critical enabler of long-term success for the new program.

People living with Parkinson's and rarer Atypical Parkinson's conditions often present with complex and fluctuating needs that require advocates to understand progressive neurological conditions, cognitive change, communication difficulties, and the intersection of health, disability, and aged care systems.

Investment in training, professional development, peer learning, reflective practice, and data capability in progressive neurological conditions would strengthen the quality, consistency, and sustainability of advocacy services nationally for people living with Parkinson's and Atypical Parkinson's. We particularly support a focus on building capability to respond to our community's complex advocacy needs.

QUESTION 9
DO YOU HAVE ANY OTHER VIEWS ON THE PROGRAM POLICY FRAMEWORK? PLEASE COMMENT (OPTIONAL).

RESPONSE:

Overall, we support the direction of the Program Policy Framework and its emphasis on outcomes, stability, transparency, and continuous improvement.

We encourage the department to clearly articulate how the new program will interface with existing aged care advocacy arrangements, including those delivered through the National Aged Care Advocacy Program and the Older Persons Advocacy Network. For people living with Parkinson's—many of whom engage with both disability, aged care, and health systems—clear interfaces are essential to avoid fragmentation and ensure continuity of support.

The greatest risk for our community is not overlap between advocacy systems, but people falling between systems or disengaging because navigating support becomes too complex and fatiguing. Clear communication, warm referrals, and shared responsibility across advocacy pathways will be critical to ensuring the program delivers on its intent.

REFERENCES

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). Final Report.
Australian Government. National Disability Advocacy Framework 2023–2025.
Australian Government. National Aged Care Advocacy Program (NACAP).
Older Persons Advocacy Network (OPAN).

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