

National Disability Advocacy Program
Department of Social Services
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Submission by **MEAction Australia**, an informal group and network comprised of individuals with ME/CFS and located all around Australia. Special mention and thanks to those patients from WA, SA and NSW who assisted with the bulk of this submission. Submitted on their behalf by group member Penelope J McMillan.

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National Disability Advocacy Program Review

This submission represents the specific concerns of people with the illness ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome).

However, we claim that these concerns apply equally to other people who share some of the same circumstances or similarly disabling conditions.

We are aware of many Australians with ME/CFS who are not receiving adequate assistance. Many people are not having their most basic needs met for food, company and secure shelter. This means that the present NDAP model has let them down. A model that identifies and supports the vulnerable people that advocacy is not currently reaching needs to be found.

This submission is weighted toward issues of justice.

This should not be used to infer that the other issues are not of tremendous importance to people with ME/CFS and other disabilities that create vulnerabilities and difficulty accessing services, including advocacy services.

1.1 How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?

Recipients of a service benefit if they can be reassured before seeking assistance that the help provided will occur along a particular path that is transparent and can be understood before seeking help.

Staff also benefit from simplicity of service models and can be expected to be proficient in those service models.

1.2 What are the drawbacks?

When models are not sufficiently open and do not include sufficient outreach, there is an increased risk that the most vulnerable people will fall outside the model.

It is essential that if models are fewer, they are carefully designed to be inclusive.

1.3 How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?

It is essential that agencies offering advocacy indicate how they provide access to advocacy for those most in need. This requires acknowledgement of the individuality and complexity of the situation for people who are most vulnerable.

2.1 How do we improve access for people with disability from Aboriginal and Torres Strait Islander communities and their families? People with disability from culturally and linguistically diverse communities and their families? People with disability in rural, regional and remote locations? People who are very socially isolated including those with communication difficulties and those in institutional care?

People with the severe form of ME/CFS need access to advocacy from their bed in their home or residential care centre. For some people such access could be electronic rather than in person. Additionally they may struggle to express themselves and need support to express their needs across several brief sessions. They may need a support person familiar with their situation and their health needs who is allowed to speak for them, with the person's consent. Both physical access and communication needs must be accommodated.

2.2 What are the strategies or models that have worked? What are the strategies that do not work?

A few people with ME/CFS have been helped through current advocacy agencies but many have had no access to advocacy or the advocacy they received was detrimental due to poor understanding of the illness.

The key issues seem to be outreach and a willingness to understand the situation from the unique perspective of the person with the disability.

3.1 What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?

When an advocacy agent becomes aware that they are not able to help an individual gain access to the help that is needed that person should not be abandoned. This should be the trigger for further action at a systemic level.

The kind of disability needs to be looked at and contact made with any groups who represent this form of disability to find out if there are other ways to help. If it becomes clear that many people with this type of disability are not having their needs met then there are problems with policy that need to be corrected. The advocacy agency should be making sure that these changes to policy are being made and that the person finally receives the required help before their case is closed.

This would help the individual not to get lost whilst systemic issues are being sorted out. The case could be passed on to another advocacy agency trained in dealing with systemic issues, but at no time should the individual's needs be forgotten about.

Ideally service providers should be allowed and able to support people not fitting into current guidelines whilst systemic issues are being sorted out.

3.2 How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as: disabled people's organisations (DPOs),the

Australian Human Rights Commission, Ombudsman organisations, aged care advocacy organisations, state disability advocacy organisations, peak bodies?

Co-design techniques could be used to allow stakeholders in the disability and advocacy arenas to develop mutually satisfactory means of collaboration and cooperation. (An example of an agency that could facilitate this process is TACSI - The Australian Centre for Social Innovation).

A crucial issue here is to ensure that stakeholders with limited ability to participate are accorded full access to all co-design processes. This includes geographic challenges as well as people whose disabilities pose difficulties with communication, intellectual engagement or physical attendance.

4.1 What steps or organisational structures should be put in place to ensure conflicts of interest do not arise, or are minimised?

Most importantly advocates or agencies should be required as part of their policy and procedures to disclose any conflicts of interest, especially when an individual is seeking support in addressing an issue that involves an agency, individual or program that is also a client of the advocacy organisation.

4.2 How do we avoid gaps between supports provided by the NDIS and advocacy funded by the NDAP?

If someone applies for NDIS and is knocked back there should be no gap in their ability to then obtain advocacy for this situation. It would be helpful for anyone who is told that they are not eligible for NDIS to be given contact details for advocacy agencies and a brief outline of how to apply for an internal review.

This is especially important for people with ME/CFS and other poorly recognised disabilities as there is some history of being denied help by NDIS and other disability service providers based solely on the diagnosis which is “not on the list” or in some other way discounted, without any recognition of the severity of disability and urgency of need for support.

4.3 What policies and strategies do we need to protect the rights of people with disability?

Most importantly it must be acknowledged and recognised in practice that the most vulnerable of people with disabilities have the least ability to act for themselves and to seek advocacy. These people need adequate time and resources in outreach services to address their special needs. It is not sufficient to presume that they will have a carer, guardian or social worker to act on their behalf.

5. Understanding and Improving Access to Justice

5.1 What forms of legal review and representation do people with disability need most?

Within the context of ME/CFS, there are a number of legal and advocacy needs. These include:

(a) **Advocacy** – Advocacy comes in a variety of forms. It may extend from the task of making enquiries for an individual, through to completion of paperwork and the coordination and assembling of evidence gathering, through to representation within courts or tribunals or acting in the capacity of guardian.

In the context of ME/CFS there is a need for advocacy and assistance in the following:

- Financial - Assistance in financial management and debt matters (noting that financial difficulties are common), including budgeting, debt consolidation, mortgagee repossessions, etc);
- Medical – Assistance in mistreatment within the medical and hospital context, including provision of information about the condition, addressing inappropriate treatment and behaviours from medical staff. In the specific context of children, there have been examples of situations where the diagnosis of ME/CFS has been provided and involvement of psychiatric care has resulted in inappropriate reattribution to conditions such as pervasive refusal syndrome, conversion disorder, Munchausen Syndrome by Proxy, etc., resulting in improper removal from care of the parents;
- Department of Community Services or its equivalent child protection agency in each state – Assistance with issues that arise with respect to the care of children within the care of persons with ME/CFS. Whilst the welfare of children is paramount, parents with ME/CFS can be subject to inappropriate and mistaken reporting, thereby requiring assistance to meet the inquiries that child protection agencies raise.
Assistance with issues that arise with respect to the needs of children with ME/CFS where their care needs are misinterpreted as neglect or abuse from the caregivers, including but not limited to absence from schooling or limited engagement with distance or home education being misinterpreted as truancy or neglect of education, and declining health being misinterpreted as due to neglect of medical needs;
- Guardianship – Assistance in the preparation of guardianship requirements for persons with ME/CFS in circumstances that dictate such assistance to occur. The condition can and does impact functional ability and/or mental capacity.
- Wills, Advance Care Directives and Enduring Power of Attorney – Assistance with testamentary issues and power of attorney issues. In ME/CFS there is an increased risk of death arising from complications of the condition and suicide. Additionally issues with respect to neurocognitive function can impact upon the ability of the person to make sound decisions. The issue of wills and power of attorney is one that is often overlooked. Persons with ME/CFS are vulnerable to being taken advantage of, influenced or simply unable to manage the day to day activities that surround self-care and financial management;
- Family Law – Assistance with relationship breakdowns and care orders. Within ME/CFS the issue of relationship breakdowns are commonplace, hence the need for assistance in this area. Again, persons with ME/CFS have functional and/or neurocognitive issues that impact upon their ability to engage in and navigate this pathway, hence an advocate is required to assist the process. Additionally parents with ME/CFS may require assistance to negotiate appropriate child care sharing arrangements;
- Centrelink - Assistance in navigating the Centrelink system, including meeting the requirements for benefits such as Sickness Allowance and the Disability Support Pension – the latter being a very complex process due to the restrictive nature of the criteria and the need for appropriately targeted medical reports.
- Insurance – Assistance with insurance matters is complex and a wide-reaching deficiency in the current system. Apart from private arrangements such as income protection, trauma insurance, and total and permanent disability there are a number of statutory arrangements that are in place to assist employees, such as workers compensation, and certain insurances within superannuation (total but temporary disability, permanent impairment and total and permanent disability). This is an area where assistance is lacking for the specific area of ME/CFS, primarily because of an inherent fear of the condition and claims surrounding it. Additionally it is an often overlooked and inherently complex area in which assistance and guidance is required;

- Discrimination – Assistance with matters of discrimination across a variety of areas, including within education, employment, services (eg rental, medical, etc) and day to day interactions is an essential aspect of ME/CFS. The contested nature of the condition leads to discriminatory practices that impact upon the ability of persons with ME/CFS to obtain access to day to day social requirements;
- Forms - Assistance in the acquiring and preparation of forms for a variety of purposes (eg NDIS, Centrelink, Insurance, Workers Compensation, Disability Accommodations, Health Care Complaints Commission, Ombudsman reports, Early release of Superannuation, etc). The neurocognitive aspects of ME/CFS can hinder accurate and appropriate completion of forms, as well as impact on the ability to meet reporting deadlines;

Advocacy can be provided on a face to face basis, via telephone, via social media/internet. Face to face advocacy is a necessity for some aspects of the issues, however with ME/CFS there are house bound patients that may be best serviced via **remote access or in-home access**. Access needs to be available in all areas of Australia – not simply capital city or major regional centres.

Of the most important financial areas of consideration there are three:

- Centrelink
- Insurance
- Workers Compensation

Financial security is the key foundation of every individual's well-being as it enables their ability to house and feed themselves, meet their day to day expenses, and most importantly, fund their ongoing medical expenses. The current system simply does not adequately meet these needs. There is a glaring and inherent gap in the existing structure.

(b) **Legal Needs** – In the context of ME/CFS there are multiple legal needs that are currently unmet by the legal profession – primarily because of a lack of understanding of the condition itself. Consequently practitioners fail to meet the needs of these people because they (a) require payment up front, (b) deny assistance on the basis of a lack of prospects (predicated on a lack of understanding the condition), (c) in the context of Public Interest Legal Bodies, there is a failure to find any “public interest” in pursuing legal assistance.

The issues identified in the above advocacy needs can and do escalate to a level where legal representation is required, including representation in courts, tribunals, commissions and the like. Services may well include preparation of documents for complaint mechanisms, statements of claim, interlocutory requirements, attendances, settlement documents, appeals and the like.

There is a dearth of available resources. The condition ME/CFS causes an inherent reluctance to engage in legal services. Legal Aid rarely provides resources for Civil Litigation – if ever in ME/CFS. Legal Centres have limited resources and are reluctant to commit such resources to “hard” cases.

(c) **Reform** – The contested nature of ME/CFS, with its multi-systemic dysfunction and combined physical and neurocognitive deficits, makes it an excellent example within which to seek understanding of the need for reforms. In ME/CFS there are specific issues that can only be gleaned through experience and insight.

There is, for example, a major problem with the current structure of the Centrelink Disability Support Pension that is causing an anomaly which creates an inherent injustice for persons with ME/CFS. In the recent case of Foote and Secretary, Department of Social Services (Social services second review) [2016] AATA 131 (4 March 2016)

"44. For completeness, I acknowledge that at the hearing Ms Foote made some very coherent, thoughtful and well-expressed criticisms of the Impairment Tables. She contended that the Tables did not adequately reflect the degree of impairment caused by conditions such as fibromyalgia and CFS,

the impact of which could be variable and cumulative depending on activity, but nevertheless pervasive and debilitating. However, as I sought to explain to Ms Foote at the hearing, notwithstanding any deficiencies they may have, the Tables are binding on me as a matter of law, and I have no discretion to depart from them."

The Applicant in this matter suffered from multiple impairments that prevented her from working. However she was unable to obtain the DSP because the legislation and impairment tables do not allow the aggregating of impairments to exceed the 20 point threshold for entitlement.

By providing advocacy through the gathering of information from clients with more complex disabilities, in order to draw to the attention of parliament to unintended "gaps" in entitlements, as well as absurdities that deny conditions with severe impairment from receiving entitlements within the intent of the legislative framework.

5.2 What barriers prevent people with disability from accessing justice?

There are a number of specific barriers that exist with respect to access to justice in the case of ME/CFS. These are as follows:

- A complete lack of understanding of ME/CFS hence an inherent reluctance to be involved in anything pertaining to the condition (noting that old prejudices that the condition is not 'real' or is 'psychological' still pervade society, hence influence the rationalisation of not engaging in this area);
- A lack of funding available to meet the basic requirements of mounting a case, hence:
Inability to fund medical reports;
Inability to fund legal advice or representation;
Inability to meet the ongoing costs of funding a matter;
It is noted that the fundamental requirements of funding litigation is income and financial resources. Often the party providing that income is the one that is the defendant, hence that source ceases.
- A complete lack of access to legal aid (who do not fund civil matters – particularly after suffering major funding cuts);

Non-capital city persons have an inability to access legal resources because:

Larger firms primarily offer no win, no pays (although very few offer to ME/CFS) whereas smaller country firms have limited resources and financial capacity hence require up-front payment;
Public transportation is poor and not suited to those with ME/CFS;
Legal practitioners rarely, if ever, attend a client's home, hence those who are physically unable to attend the office are precluded;
Remote communities often do not have legal services, or if they do, do not have the capacity to handle a complex matter such as ME/CFS.

- An inability to engage in the legal and quasi-legal framework because of the inherent disability arising from the ME/CFS, whether it be due to geographical isolation, physical incapacity, or mental incapacity).

5.3 What models of legal advocacy are the most effective?

In terms of a model there are several options that can be effective:

- (a) Direct Advocacy – Direct advocacy requires the direct employment of advocates by the NDAP. This approach holds benefits by:
- (i) Funding wages as opposed to hourly rate, is a more cost effective approach;

(ii) Pooling specialised resources, skills and knowledge within an in-house structure, which can enable more effective representation;

(iii) Holds potential to send legal representation into the field (eg like the Aboriginal Legal Centre does with remote communities) where it is needed, particularly in ME/CFS where patients are housebound with little to no available resources to enable them to prepare any dispute.

(b) Funded Advocacy – Funded advocacy provides funding to Legal Practitioners in the location of the client (or for the client if external). This is a process that operates in a similar manner to Legal Aid. Funded advocacy could allow the client to identify and select available solicitors who require ongoing funding of advice and representation, thereby removing the financial barrier to accessing justice.

(c) Legal Centres – Funding of legal centres to provide assistance to clients who have a disability such as ME/CFS, provides an available community legal centre to provide services in this specific area. This could enable legal centres to provide centralised services within certain regional centres and act as a defacto direct advocacy centre.