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ACT Lifetime Care and Support Commissioner's Office

ACT Lifetime Care and Support Qualitative Review 2019

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List of documents consulted

Document	Reference
ACT Lifetime Care and Support Participant Feedback Research 2016 – Research Report	Internal
ACT Lifetime Care and Support Participant Feedback Research 2017 – Research Report	Internal
ACT Lifetime Care and Support Participant Feedback Research 2018 – Research Report	Internal
ACT Lifetime Care and Support Scheme: Participant Survey 2019	Internal
NSW icare Revised Communications Protocol 2018	Internal
NSW icare My Plan Toolkit Booklet *January 2015*	https://www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/planning-with-an-injured-person/#gref
NSW icare My Plan Information Sheet *January 2015*	https://www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/planning-with-an-injured-person/#gref
NSW icare My Plan Planning Facilitator's Manual *January 2015*	https://www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/planning-with-an-injured-person/#gref
NSW icare Decision Making Framework *August 2018*	Internal

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Executive Summary

The Lifetime Care and Support Commissioner of the ACT is responsible for the review of the operation of the Lifetime Care and Support (Catastrophic Injuries) Act 2014 up to 30 June 2019. This report provides an independent review of the qualitative aspects of the Lifetime Care and Support Scheme's (the Scheme's) objectives for the period, to contribute to the Commissioner's review. In particular, an assessment is given of the extent to which the Scheme has been effective and efficient in responding to the reasonable and necessary treatment and care needs of people who have suffered catastrophic injuries and are part of the Scheme. Hereafter the qualitative review presented in this document will be referred to as 'the review'.

The ACT Lifetime Care and Support Participant Feedback Research, reported annually from 2016 to 2019 inclusive, forms the evidence base to address specified review objectives. Research conducted in 2016, 2017 and 2018 relates to motor vehicle injury participants, while the 2019 research relates to work injury participants. This report considers evidence across the research years, as appropriate.

Two main principles guide the review. Firstly, it is necessary to adhere to the conditions of consent under which the research was undertaken and therefore preserve anonymity and prevent re-identification of participants. Secondly, given that issues and challenges will occur from time to time in Scheme implementation given the complex needs of participants, the sometimes unpredictable aspects of recovery, and people's different circumstances, this review recognises that what is critical to the Scheme's success in meeting needs is that systems and communications are in place to identify and rectify issues where they occur, in a manner that is timely and satisfactory to participants.

Four review points structure this report.

Review point 1 addresses whether, and to what extent the Scheme treatment and care services for participants in the motor vehicle injury and work injury categories have been delivered efficiently and effectively.

The evidence is very positive. The financial support for treatment, rehabilitation, care and equipment, and assistance navigating health systems and finding appropriate medical and allied health specialists, are frequently cited by respondents as particular sources of overall satisfaction.

Within respondents' understanding of the Scheme's scope, most respondents are very positive about the way in which the Scheme meets their needs. A tension persists between the Scheme responding to identified needs and the desire to have a list that gives all possible benefits a participant may be entitled to within the Scheme. The interface between these is the case manager and/or coordinator and their experience, knowledge and communication skills. It is understood that the delivery of Scheme benefits happens within a context that may include barriers unrelated to the Scheme. An example given is the approval of vehicle modifications in a situation where a participant lacked personal funds to provide a car meeting the requirements for modification.

Overall the Scheme meets needs and where issues occur, the resolution is usually found with the assistance of the case manager and/ or coordinator. Further, there are systems and mechanisms in place for people to raise their issues, and to resolve them as quickly as possible. The complaints and dispute processes have been utilised as a mechanism to resolve issues, where appropriate, and resolution of complaints and disputes has occurred within the specified timeframes. Systems and

processes that support delivery of services to participants are continually reviewed and tested against research and feedback and revised to provide better services.

Review point 2 considers participants' perceptions of the impact of the transfer of administration and delivery of the Scheme benefits from the ACT government to the NSW Lifetime Care and Support Authority (NSW LTCSA) in September 2015. The evidence is that the transfer was implemented seamlessly.

Review point 3 considers participants' perceptions of the improvements (including system design and administrative changes) made to the Scheme during the period.

Improvements introduced since 1 July 2014 are considered in this review, including the introduction of My Plan, and the revision of the communications protocol.

My Plan was introduced in January 2015 in NSW and ACT Schemes to replace traditional rehabilitation planning with person-centred planning to enable the participant to exercise greater control over goal development and associated service planning. Perceptions of My Plan are positive and note that it facilitates tailored supports that consider a participant's injury-related needs in the context of their personal circumstances and wishes. There is also evidence that it has assisted in promoting the continuity of services and care in the lead up to the two-year review for interim participants seeking lifetime status in the Scheme.

Revisions of the communications protocol from 2014 to 2018 set a benchmark for the minimum level of communication that is expected to occur between front line staff and participants. While few issues were raised in the ACT research, a communication issue was raised early in the research and a recommendation was to consider the provision of information on the two-year review process six months in advance. The revised protocol describes the expected coordinator conversations with interim participants and includes coordinator contact with interim participants at six months prior to the expiration of the interim participation period to explain the process and what to expect. From 2018, it was made explicit that this conversation is to address any fears or anxieties about the process and assist with making plans to transition out of the Scheme if this is likely to occur.

Finally, review point 4 examines participants' perceptions of whether changes are necessary to improve the way services or benefits under the Scheme are assessed and delivered to them or to improve the effectiveness of the services provided to them.

In the context of very positive feedback, there are few issues existing in the evidence that have required a response. Issues have been in relation to communication, such as discussions on the two-year review noted above, and these have been addressed by revisions to the communications protocol. Two further items are noted. There is a desire for clarification of the role of the National Disability Insurance Scheme (NDIS) and how it may intersect, if at all, with the Scheme. There is also a sense for some that the Scheme is limiting by remunerating only formal carers from a care agency, rather than also remunerating family members who may choose to provide the care, though there is a clear understanding that the latter remuneration is outside the scope of the Scheme provisions

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Chapter 1: Review Objectives and Evidence Base

1.1 Overall Objective

The Lifetime Care and Support Commissioner of the ACT requires assistance in undertaking a review of the operation of the Lifetime Care and Support (Catastrophic Injuries) Act 2014 up to 30 June 2019. The Lifetime Care and Support (LTCS) Scheme (the Scheme) commenced on 1 July 2014 for the motor vehicle accident injuries stream, and on 1 July 2016 for the work injuries stream from, yielding five and three years of operation respectively.

The purpose of the present report is to respond to the terms of reference in the request for quote (issued by the LTCS Commissioner of the ACT on 9 August 2019) by providing an independent assessment of the qualitative aspects of the Scheme's objectives. In particular, an assessment is given of the extent to which the Scheme has been effective and efficient in responding to the reasonable and necessary treatment and care needs of people who have suffered catastrophic injuries and are part of the Scheme.

1.2 Specific Objectives

(i) Review whether, and to what extent LTCS Scheme treatment and care services for participants in (a) the motor vehicle injury category and (b) the work injury category have been delivered efficiently and effectively. [1]

(ii) Review participants' perceptions of the impact of the transfer of administration and delivery of the Scheme benefits from the ACT government to the NSW Lifetime Care and Support Authority (NSW LTCSA) in September 2015.

(iii) Review participants' perceptions of the improvements (including system design and administrative changes) made to the Scheme; and

(iv) Review participants' perceptions as to whether changes are necessary to improve the:

(a) way services / benefits under the Scheme are assessed and delivered to them; and

(b) effectiveness of the services provided to them through the scheme.

1.3 Evidence Base

The participant and worker feedback research projects reported in 2016, 2017, 2018 and 2019 form the evidence base to address the review objectives.

Research conducted in 2016, 2017 and 2018 relates to motor vehicle injury participants, while the 2019 research relates to the work injury participants. Also, each report has a focus of enquiry, so not every report is relevant to every objective. This review considers evidence across the research years, as appropriate.

It is noted here that the small, finite population imposes requirements of the research methodology that are relevant for this review. A census is appropriate for this population size (subsampling is not

[1] For this review, the term 'participants' will be used to refer to those people in the motor vehicle injury category and the work injury category.

practical). However, a quantitative survey is not appropriate even with a census as converting output to percentages to track changes across years will not meet assumptions of statistical testing. The approach employed has been to use a qualitative method of face-to-face in-depth interviews, following an agreed discussion guide, with thematic analysis incorporated into reporting. The nature of the reported output cannot prevent re-identification. Therefore, for this population it was necessary in advance of any research activity to acknowledge and manage the lack of a guarantee of anonymity.[2]

To be consistent with the above, and prevent re-identification occurring via the present review, pooled evidence will be considered and described here. No quotes will be used. Reference will usually be made to respondents in general. If an example may in any way point to a group or single participant, an alternative scenario to illustrate the point will be provided based on the reviewer's experience with the NSW Participant Feedback Research (2009-2019). For the NSW research, both anonymity and confidentiality are in place due to the nature of the sub-sampling from the significantly larger population. The text will note where this occurs.

1.4 Approach

The approach in this review is to understand that issues and challenges will occur from time to time in Scheme implementation given the complex needs of participants, the sometimes unpredictable aspects of recovery, and people's different circumstances. What is critical to the Scheme's success in meeting needs is that systems and communications are in place to identify and rectify issues where they occur, in a manner that is timely and satisfactory to participants.

Chapter 2: Review Point 1 - Effectiveness and Efficiency

Review whether, and to what extent LTCS Scheme treatment and care services for participants in (a) the motor vehicle injury category and (b) the work injury category have been delivered efficiently and effectively.

2.1 Definitions of effectiveness and efficiency

Assessing the effectiveness and efficiency of Scheme treatment and care services from the point of view of participants speaks to the quality of the Scheme service delivery model.

In this context of service delivery, *effectiveness* is defined for this review as the delivery of treatment and care services within Scheme provisions that meet the specific needs of participants.

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[2] This was managed in the following ways:

(i) The primary approach letter from the Commissioner's Office stated in writing that accepting or declining the invitation to participate in the research would in no way affect access to services, equipment or other rehabilitation supports at the time or in the future.

(ii) There were ten business days to consider whether to opt out of the research or not, so that potential respondents did not feel rushed or pressured and had time to make further enquiries if they wished.

(iii) Further, communicating to respondents that confidentiality can be maintained was important. For example, it helped to reassure respondents that their case management relationship will not be negatively impacted if they voice concerns with communication issues.

In this same context, *efficiency* is defined for this review as the timely delivery of treatment and care services within Scheme provisions.

The evidence base by which to assess effectiveness and efficiency is the feedback from respondents in the 2016 to 2019 research reports. Respondents include participants and their nominated representatives who were interviewed as part of the LTCS participant research surveys.

2.2 The context of perceptions

Respondents often comment that they did not know the Scheme existed before their injury and therefore did not know what to expect, nor have a standard with which to compare the Scheme provisions. Early post-injury, at least, respondents may speak of their needs in terms of provisions or what services or treatments are applied for. This is relevant in that asking about whether needs are met may be understood by the respondent as confined to whether what is applied for is approved, or received according to what was approved. Further, the gratitude expressed by respondents for the existence of the Scheme, and the desire by many not to be seen as asking for 'too much', is related to the overwhelmingly positive responses to the Scheme and the way in which it meets needs. It was important in interviews to listen and acknowledge gratitude so that respondents could take that as understood by the interviewer and move onto discussion of their experiences and perceptions.

2.3 Overall perceptions of having needs met

One way of assessing whether, and the extent to which, treatment and care services have been delivered effectively is to consider respondents' feedback on whether and how the Scheme has met needs overall.

To gain their overall view, respondents were given a definition of the Scheme and then asked about their satisfaction or dissatisfaction with how the Scheme meets their needs.

> *The Lifetime Care and Support Scheme is run by Lifetime Care and Support and pays for reasonable and necessary treatment, rehabilitation and care of people with serious injuries from a motor accident or work injury.*

Overall, across the years, the feedback is overwhelmingly positive. The financial support for treatment, rehabilitation, care and equipment, and assistance navigating health systems and finding appropriate medical and allied health specialists, are frequently cited by respondents as particular sources of overall satisfaction.

As noted above, those newer to the Scheme are more likely to equate needs with what is applied for and agree needs are met if services are applied for and received. Indeed, in instances where respondents indicated their needs were partially met, the issue was not about whether an item had been applied for in the first place, but rather whether a service or piece of equipment had been approved. An example is the number of hours that a service was provided, rather than whether a service was provided.

There is some evidence that external factors have impeded Scheme benefits being realised in some instances. An example to illustrate this is the approval of vehicle modifications in a situation where a participant lacked personal funds to provide a car meeting the requirements for modification.[3]

In one year's research, while three of the four respondents were 'very satisfied' with the way the Scheme meets needs, a fourth respondent indicated 'neither satisfied nor dissatisfied' as a halfway point between feeling very positive about the management and personnel involved in the Scheme implementation and feeling negative about some delays and the rejection of a request.

It is noteworthy that for this respondent, positive relationships with service providers, the case manager and coordinator, entered into the decision on how to respond to the question of whether the Scheme meets needs. Communication with case managers and coordinators is pivotal to needs being met and is discussed below as it relates to specific needs being met, issues identified, and solutions found.

2.4 Goals and planning, relationships and effectiveness

The Scheme is designed to be responsive to identified needs that fall within its terms. If a need is not identified, then it cannot be met. The Scheme's ability to identify needs, and to meet them effectively and efficiently over time, depends in part on the knowledge and expertise of the case manager and coordinator, and on the relationships with and between them.

2.4.1 Evidence relating to relationships

Respondents were very positive about their relationships with their current case managers and coordinators. It is noted that the primary relationship is usually with the case manager, especially for interim participants. Respondents have spoken of their case managers and coordinators taking time to listen to them, explaining things clearly, involving them in decision making and making appropriate contact with them.

There is variation in the effectiveness of support noted: one respondent spoke of a relationship breakdown with their case manager that they felt resulted from the case manager's lack of understanding of their injuries. When the coordinator was alerted to the issue by a third party, a more suitable case manager was sourced, access to Scheme supports was improved, and respondent feedback was positive.

Face-to-face contact is highly valued in establishing and maintaining relationships to build rapport and trust. The personal contact with the coordinator in the establishment of a new case manager relationship in the above example was remarked on as important to a positive start. This example demonstrates that where an issue occurred, a satisfactory resolution was found with the help of the coordinator.

This example also illustrates the importance not only of finding the right case manager for a participant or worker, but also the need for ongoing, independent and coordinator-initiated communication with participants in order that service provision, including case management, may be actively monitored and any disruptions or issues managed and satisfactorily resolved. This point is returned to in section

[3] The example of vehicle modifications to illustrate the point is from the NSW Scheme rather than the ACT Scheme so as to preserve anonymity.

4.4.2 as it relates to the revised communications protocol (2018) which explicitly includes this proactive communication.

Scheme goal development and planning are structured to consider a participant's personal circumstances, including the level of family support. It is noted in the example above that a lack of family advocacy and supports exacerbated the vulnerability of the participant who lives with multiple complex injuries. This demonstrates that communication and service protocols have the flexibility to offer greater support to those participants who are particularly vulnerable. This may entail, as it did for this participant, a case manager attending a first appointment with a new provider or medical specialist in order to ensure that a complete history is provided, questions are raised and addressed, and outcomes are recorded to share with other service providers as relevant and appropriate.

Some respondents believed that the coordinator is 'above' the case manager in a hierarchy. In these instances, there was no evidence that this misperception impacted relationships or Scheme supports. Nonetheless, it was suggested that reiterating information on the case manager and coordinator roles, at least while the participant has interim status, will promote open lines of communication and reinforce intended ways of working. Clear information for participants and their families on these roles, and who to contact in different circumstances, is available on icare's website.[4] While icare's communications protocol describes the roles of icare staff, with a focus on the coordinator, it does not specify that information on roles is to be reiterated. However, the implementation of the coordinator role according to the revised communications protocol provides opportunities to clarify the case manager and coordinator roles, and establish and maintain open lines of communication.

2.4.2 Formulating goals and planning

Planning starts before the participant leaves hospital. Since January 2015, My Plan has been used for person-centred planning to enable the participant to exercise control over goal development and associated service planning. There is consistent evidence that participants have engaged with the goal development process, and that the pre-approval process is understood. It is also noted by a family member that the treating team for a participant took the time to identify needs beyond what the participant was aware of. Others commented on how they appreciated that their case manager completes paperwork and the organisation required for applications and any associated assessments.

All respondents spoke of receiving decisions and either being able to understand the decision and the reasons for it, or seeking clarification from the case manager or coordinator. It was always appreciated if a coordinator rang to communicate treatment and/ or care decisions personally, in addition to the certificate letter and case manager advice.

However, a tension has been observed between the Scheme being responsive to needs, and participants and their families feeling confident that they are accessing all they are eligible to access within the Scheme. A question has been *how do I know what else might be available?* This was evidenced early in the ACT Scheme implementation, and less so in later years. Reiterating information on the Scheme's scope after the initial intensity of the trauma, perhaps at three to six months, is part of the communications protocol to address this.

[4] https://www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/case-managers/working-with-a-case-manager/

2.5 Service and equipment delivery and management to support goals and meet needs

Respondents have spoken of receiving a range of services, attendant care, equipment and repairs as well as modifications. Experiences vary, though overall respondents have reflected very positively. Some respondents have commented on their surprise and gratitude for how tailored services have been to the participant's needs and circumstances. This includes matching carers to the participant's age, gender and interests where possible.

Unsurprisingly, there were instances where services and equipment issues required attention to resolve. In each circumstance the case manager or coordinator was involved. Issues included the following:

- A delayed payment to a service provider;
- Some service providers not knowing enough about the Scheme for ease of appointments and payment processes;
- Attendant carers from a particular agency not turning up, requiring a change of provider;
- An unsatisfactory level of care from a particular agency, requiring a change of provider;
- Delays with some parts for, or servicing of, larger pieces of equipment.

There is an understanding that delays can be due to suppliers. However, one respondent expressed frustration about the need for assessments, particularly when the item or service was low-cost.

Importantly, a complaints and disputes process has been in place since Scheme inception and some participants have engaged positively with these processes as a way of ensuring their needs are met within the Scheme's scope. As at June 2019, eleven level 1 complaints and two level 2 complaints have been received and resolved within KPI timeframes. One treatment and care dispute was lodged and was resolved in the participant's favour within the guidelines' timeframes.

2.6 Two-year review

Research sought to understand whether the two-year review to determine ongoing eligibility for the Scheme caused any interruptions to Scheme benefits for participants.[5] The evidence was that there were no interruptions. Rather, respondents spoke of the treating team ensuring planned treatments or surgeries occurred within the two-year window. Another respondent commented that their attendant care provider continued to support them in a 'business as usual' manner throughout the six months leading up to the decision on their eligibility for lifetime status, and continued to do so thereafter as they remained in the Scheme.

2.7 Review Point 1 Conclusion

Within respondents' understanding of the Scheme's scope, most respondents are very positive about the way in which the Scheme meets their needs. A tension persists between the Scheme responding to identified needs and the desire to have a list that gives all possible benefits a participant may be entitled to within the Scheme. The interface between these is the case manager and their experience,

[5] All participants commence as 'interim participants' for up to two years. After two years, an interim participant may be eligible to become a 'lifetime participant'. Prior to the end of the interim participation term, the participant is assessed for lifetime participation. This process is referred to as the '2-year review'. (Children cannot apply for lifetime eligibility until they are at least five years old.)

knowledge and communication skills. It is understood that the delivery of Scheme benefits happens within a context that may include barriers unrelated to the Scheme. An example referred to the approval of vehicle modifications in a situation where a participant lacked personal funds to provide a car meeting the requirements for modification.

Overall the Scheme meets needs and where issues occur, the resolution is usually found with the assistance of the case manager and/ or coordinator.

Further, there are systems and mechanisms in place for people to raise their issues, and to resolve them as quickly as possible. The complaints and dispute processes have been utilised as a mechanism to resolve issues, where appropriate, and as noted above in Section 2.5, resolution of complaints and disputes has occurred within the specified timeframes. Systems and processes that support delivery of services to participants are continually reviewed and tested against research and feedback and revised to provide better services.

Chapter 3: Review Point 2 - Transfer to NSW

Review participants' perceptions of the impact of the transfer of administration and delivery of the Scheme benefits from the ACT government to the NSW Lifetime Care and Support Authority (NSW LTCSA) in September 2015

3.1 Awareness of the transfer of administration

The 2016 research with the Lifetime Care and Support stream is relevant to the assessment of this review point.

In this research, respondents were read the following statement:

> *You may know that from 1 September 2015, the administration of the Lifetime Care and Support Scheme transferred from ACT to NSW, and a letter was sent to you in August from the Lifetime Care and Support Commissioner informing you of this change.*

There was moderate awareness of the transfer from ACT to NSW-based administration of the Scheme: for each of the participants at least one respondent was at least partially aware of the change. For some, the primacy of the case manager relationship made the change less apparent; that is, as their case manager did not change, and they mainly dealt with them, this continuity in communications indicated to them that the Scheme implementation was 'business as usual'.

3.2 Changes to coordinator relationships or services or equipment provision

Respondents were also asked whether since that time of transfer there had been any change in the frequency or nature of their contact with their coordinator, or any change to the services or equipment the Scheme provided.

All but one noticed no appreciable difference in coordinator contact frequency or nature as they primarily dealt with their case managers and other treating team members. The remaining respondent noticed a positive change in their relationship with their coordinator.

There were no reported changes to the services or equipment the Scheme provided as a result of the transfer. For two participants, delays with equipment provision or repair had been an issue in 2015, though both were resolved in early 2016. At the time of interviewing (May 2016) there were no

outstanding issues with equipment. The only comment regarding services was a difficulty accessing a particular specialist allied health professional in a suitable time period. However, the delay was seen as a reasonable consequence of high demand for a profession with few specialists.

3.3 Review Point 2 Conclusion

The evidence indicates the transfer to NSW administration was seamless for participants. Any issues with Scheme provisions, such as a delay to receiving a piece of equipment, were unrelated to the transfer to NSW administration.

Chapter 4: Review Point 3 - Perceptions of improvements

Review participants' perceptions of the improvements (including system design and administrative changes) made to the Scheme

Note: A review of the transfer of administration to NSW is covered above in Ch 3.

4.1 Improvements that relate to NSW and ACT Schemes.

As NSW administers both the NSW Lifetime Care and Support Scheme and the ACT Lifetime Care and Support Scheme, several improvements in system design and administration have been made, and some of these relate to feedback contained in the ACT participant research.

There is considerable overlap between feedback from the two Schemes which is not surprising given the similarity of eligibility criteria, service delivery model, communication protocol, and administering body. Since the NSW Scheme predated the ACT Scheme, some system and design improvements have predated the ACT Scheme implementation, to the latter Scheme's benefit.

Improvements introduced since 1 July 2014 are considered in this review. Evidence is reviewed in relation to the:

- introduction of My Plan;
- introduction of the Decision Making Framework; and
- revision of the communications protocol.

For the NSW and ACT LTCS Schemes, it must be noted that where significant changes are introduced, there is a period of time for the changes to be embedded in practice and before benefits will be realised in the population and in turn be evident in any research. In the case of the revision to the communications protocol that occurred in late 2018, for example, the changes will be related to concerns or issues raised in the past to note whether and how the revision addresses them. Given the proximity of the revision to the next available research report in 2019, there is insufficient evidence available to assess the revision against the 2019 findings. For other improvements, such as My Plan, the change occurred so close to the beginning of the ACT Scheme's commencement that evidence is assessed to understand any benefits or difficulties for participants.

4.2 My Plan

4.2.1. My Plan Introduction

My Plan was introduced in January 2015 in NSW and ACT Schemes to replace traditional rehabilitation planning with person-centred planning to enable the participant to exercise greater control over goal development and associated service planning.

My Plan is intended to take a holistic approach that enables goal identification for the participant with the understanding that the person may have some goals that may not be supported within the terms of the Scheme but that may be supported by external organisations and processes.

At the time of the first research report (June 2015), some participants had commenced in the Scheme with a Community Living Plan, and some with a My Plan, depending upon the timing of their Scheme entry. All participants transitioned across to the My Plan process.

4.2.2 Evidence relating to My Plan

Initial research was conducted near the commencement of the ACT Scheme implementation in 2016 and by definition involved *interim* participants and their family members. To some extent evidence relating to goal formation and planning services is complicated by the early phase of learning about the Scheme. Reflecting on that early stage, some respondents commented that they wished that they were clearer on what was in and outside the Scheme's scope, so they felt more confident about whether to raise queries with their case manager. This resonates with the previously noted desire not to be seen to be asking for 'too much'. This meant that sourcing out-of-scope supports was delayed in one instance.

Later research provides evidence that the My Plan process better prevents this lack of clarity and allows for referrals to other organisations as appropriate. Nonetheless, an uncertainty about how the Scheme interfaces, if at all, with the National Disability Insurance Scheme (NDIS) persists. This is also discussed in section 5.2 below.

Further, there is evidence that the My Plan approach is a foundation for tailoring services and supports to the participant in a collaborative manner, and that it is not a 'cookie-cutter' approach.

There is also evidence that the My Plan approach assisted in promoting a continuity of services and care in the lead up to the two-year review. However, early evidence was that for some participants and family members there was a lack of clarity in advance of the two-year review regarding what supports might be available to a participant and their family, were the participant deemed to be no longer eligible. At the time of writing this review, there are no participants who have exited the ACT Scheme. Some comments have reflected that 'all's well that ends well', i.e. gaining lifetime status means there is no ongoing disadvantage due to that lack of clarity. Subsequent to the early research, the two-year review has not returned as a focus of research. However, the revision of the communications protocol specifically addresses the involvement of the coordinator in preparations for the two-year review and any potential exit. This is described further in section 4.4 below.

4.3 Decision Making Framework (DMF) August 2018

4.3.1 Introduction of the DMF

The DMF was introduced in August 2018 to triage risk and to produce quicker low-risk decisions. NSW data indicate that it has resulted in 80 per cent of low risk service requests being made within one day.[6]

[6] 2018 Review of the Lifetime Care and Support Scheme, Report 70, February 2019, ISBN 9781922258755; https://www.parliament.nsw.gov.au/lcdocs/inquiries/2511/Final%20Report%20-%202018%20review%20of%20the%20Lifetime%20Care%20and%20Support%20Scheme.pdf

4.3.2 Evidence relating to the DMF

The DMF has not been a specific focus of the ACT research. The ACT research prior to the DMF introduction has noted instances where respondents commented on delays gaining access to approved services, equipment or repairs. Sometimes this was understood to be on the supply side, rather than due to Scheme personnel or processes. For one respondent the source of the delay was not known, though once identified, the delay was resolved to their satisfaction in a timely manner. Home and/ or vehicle modifications were noted to be time-consuming because of their nature, though delays were not commented on in the ACT. Comment was made that anything medical was actioned immediately, though non-medical requests or issues may require time for assessments to be conducted.

The most recent research that was conducted after the DMF was introduced does not mention delays. As the DMF has not been a particular focus of research in the ACT, the review is unable to comment, other than to note that no issues relating to delays came up in the research once the DMF was implemented.

4.4 Communications protocol revision October 2018

4.4.1 Revision of the communications protocol

The revised standards set a benchmark for the minimum level of communication that is expected to occur between frontline staff and participants. This includes expectations for advising on funding decisions for low, medium and high-risk decisions as defined in the DMF.

4.4.2 Evidence relating to the revised communication protocol

An early research recommendation was to consider providing information to participants to clarify the case manager and coordinator roles and promote contact by the coordinator. The early evidence noted that there was some confusion on the part of respondents regarding the role of the coordinator and the basis for an ongoing relationship with them. Given the supportive contribution that contact with their coordinator can offer a participant and/ or the nominated person, and the apparent lack of recent coordinator contact for some interviewed participants, it was sensible to suggest coordinators continue or initiate regular and ongoing contact for all participants and/ or their nominate persons. This was over and above responding to participant-initiated contact.

It is noted that from 2014, the communications protocol included minimum communication requirements for direct contact with a participant/ worker/ guardian/ person responsible to:

(i) make phone contact once per quarter (interim and lifetime); and

(ii) undertake face to face visits for interim participants biannually.

This coordinator-initiated contact includes specifically seeing how the participant and their family is progressing towards their recovery and rehabilitation goals and whether services and supports are adequately and appropriately meeting their needs. Case management is a service to the participant and so would be a part of this process.[7]

[7] The protocol also acknowledges that participants may prefer less contact than that specified in the revised standards and that any agreement reached for contact less than the minimum standard is to be clearly recorded.

Positively, evidence from later years does not note a lack of coordinator contact.

Another early research recommendation was to consider the provision of information on the two-year review process. It was noted that information may best be provided three to six months in advance of the two-year review process. It was also noted that this information may be provided on the assessment process itself and on any available supports (within or external to the Scheme) to transition from the Scheme should the participant be deemed ineligible for lifetime status.

The expected coordinator conversations described in the 2014 and 2018 revisions of the protocol against the interim participant stage includes coordinator contact with interim participants at six months prior to the expiration of the interim participation period to explain the process and what to expect. From 2018, it was made explicit that this conversation is to address any fears or anxieties about the process and assist with making plans to transition out of the Scheme if this is likely to occur.

4.5 Review Point 3 Conclusion

Perceptions of My Plan are positive and note that it facilitates tailored supports that consider a participant's injury-related needs in the context of their personal circumstances and wishes. The introduction of the DMF and revisions of the communications protocol are positive in that they address issues noted in the Scheme's operation in the ACT.

Chapter 5: Review Point 4 - Perceptions of necessary changes

Review participants' perceptions as to whether changes are necessary to improve the:

(a) way services / benefits under the Scheme are assessed and delivered to them; and

(b) effectiveness of the services provided to them through the Scheme.

5.1. Introduction

In the context of very positive feedback, there are few issues existing in the evidence. The two items covered below relate to Scheme scope rather than to recommending improvements to the way services and benefits are assessed and provided within the Scheme.

5.2 Clarification of the NDIS role

Across the years, respondents have queried how, if at all, the NDIS may relate to the Scheme. It is unclear whether being in the Scheme precludes making requests to the NDIS, or whether the NDIS may offer services or benefits that are different to those supported by the Scheme. While individuals may raise queries with the case managers or coordinators, it may be helpful to consider repeating existing information on this, or developing materials if updated information is available. This will support standardised information and reassure participants that they are not missing opportunities that may be available to them or clarify any opportunities that may exist.

5.3 Support for Family members' roles

The legislation provides for coordinators, case managers and attendant care services, among other supports. However, family members who are in a position to, may choose to take on a management and/or care role, to varying extents, in order to best support their participant.

The Scheme is flexible in that it has the mechanisms to take into account the varying levels of informal supports that a family may provide and assist participants accordingly. Understanding the family context is also critical to the planning and delivery of Scheme services and supports and is embedded into the My Plan process.

Across the NSW and ACT populations there are several situations in which a participant and their family may decline attendant care or take up less than is approved. For example, cultural reasons may exist for some, while the age of the participant may be a factor for others. Further reasons may involve the closeness of the relationship between the participant and a family member, or particular resources or capabilities a family member may have.

However, where family members who are in a position to, and choose to take on a significant carer's role, and/or tasks that might overlap to some extent with coordinator or case manager roles, or substitute for attendant care, formal acknowledgement of their input is considered by them to be only partial. While there is a sense for some that the Scheme is limiting by remunerating only formal carers from a care agency, there is a clear understanding that such remuneration is outside the scope of the Scheme provisions.

5.4 Review Point 4 Conclusion

As noted above, in the context of very positive feedback, there are few issues existing in the evidence that have required a response. Issues have been in relation to communication, such as discussions on the two-year review, and these have been addressed by revisions to the communications protocol. The further suggestions that are made relate to the Scheme's scope, as noted in 5.2. and 5.3 above.