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Introduction

The Exceptionally Complex Support Needs (ECSN) program assists NDIS participants (aged 18 and over) with complex needs who are experiencing crisis, or at risk of entering a crisis situation. The focus is on strengthening support coordination and mainstream responses. Marathon Health are the ECSN provider for New South Wales, Australian Capital Territory and interim provider for South Australia.

Program aim(s)

Function 1 – Sector and community development and delivery

Function 1 aims to support growth and development of organisation and sector practice capability to improve community access for participants with complex support needs. In delivering this function, we are working to build stakeholder relationships in the community, remove barriers for participants with exceptionally complex support needs, facilitate promotion of knowledge exchange, identify sector patterns and perform ongoing program monitoring and evaluation.

Our original approach to sector and community development was to engage stakeholders through a series of regional workshops across NSW and the ACT from March 2020. Following advice from the Australian Government about physical distancing during the COVID-19 pandemic crisis, we ceased in person activities, transitioning to virtual service delivery and engagement.

Relationship building with stakeholders has enabled the ECSN team to identify areas that require further investigation to strengthen support coordination and mainstream responses to participants in crisis. Importantly, within the program’s footprint, relationships have developed with NDIS transition roles in local health systems; resulting in more coordinated crisis responses within these systems. Relationships with existing programs including the Integrated Service Response program and Pathways to Community Living Initiative were formed and continue to be invaluable. Increased joint collaborations with the NDIA are being explored.

Function 2 – Subject Matter Expertise (SME)

The aim of this function is to build systemic capabilities through the application of knowledge and skills to enhance service provision, procedure and the knowledge and skills of those who provide direct support to the target group. This function is coordinated by the Portfolio Manager, Specialist Support Coordinators, Support Coordinators and Positive Behaviour Support practitioners.

The SME team is comprised of professionals with experience across various professions including psychology, speech pathology, social work, Aboriginal health, local area coordination and child protection.

The team are developing resources and frameworks to increase understanding of how to better engage with ECSN participants at risk/in crisis and disability systems to enable delivery of best practice. This includes: service disengagement, navigating and working with the participant to negotiate mainstream systems, identifying risk factors for crisis, crisis planning and practitioner self-care.

A consultation and peer support service has also been established. The service is targeted at assisting support coordinators having difficulty helping participants with complex support needs and/or in pre-crisis or crisis. Referrals are made through the ECSN webpage and triaged by the Portfolio Manager. Some referrals require a full consultation, whilst others may only require peer support from one ECSN staff member to assist the referrer to work through the problem.
Function 3 – Crisis response and referral

Crisis referral is a critical arm of the ECSN program. The aim of this function is to coordinate integrated responses for NDIS participants experiencing a crisis. This service is for current (and access met) NDIS participants over 18 years. Crisis referrals occur when a participant’s disability related supports suddenly become ineffective, inadequate or absent during times when the NDIA cannot immediately respond. It is active between 5pm and 9am Monday to Friday, over weekends and on Public Holidays.

Approved Referrers include health (hospitals, mental health), ambulance, police and justice, as nominated by the relevant State/Territory Government.

Each call is triaged by the Portfolio Manager before being allocated to rostered ECSN staff. Analysis of the data captured from this service can be reviewed below.

Function 1

Sector and community development and delivery

Between February and July 2020, the ECSN team connected with 1,345 registered support coordination providers, facilitated 86 stakeholder engagement activities and conducted an online practice survey of support coordinators that collected 99 responses. Through each engagement, the team sought to understand common themes and challenges experienced by support coordinators and mainstream services in supporting participants with complex needs during points of crisis and identify good practice for replication and further promotion.

Facilitated engagements

Engagement activities focused on creating awareness of the program and collaborative planning with government and mainstream services and approved referrers. The team also engaged with multi-sector groups and advocacy services. More recently, we have included regular engagements with NDIA Provider and Community Engagement teams.

During facilitated engagement activities, common themes and challenges were raised including how the support coordination role was understood and translated into practice – particularly in relation to crisis:

- Skills navigating mental health systems
- Understanding support needs of psychosocial participants
- Ability to identify changes in functional capacity
- Understanding and responding to behaviours of concern

Market thinness was identified as a challenge – notably in remote areas. However, it is important to note that markets are still developing. Prominent barriers included:

- Access to specialist support services
- Difficulties identifying service specialisation (such as mental health)
- Unsuitable supported living options

Other significant themes were:

- Timeliness of crisis responses ranging from lack of contingency planning
- Disability provider flexibility
- Access to appropriate emergency housing and delays due to internal NDIA systems
Communication and coordination between providers and systems that prevented sharing of necessary information about a participant was also identified as an area that requires further investigation. Below, a quote highlights provider difficulty:

“Health doesn’t have governance over the disability sector so we are relying on a collaborative approach; unfortunately, often this engagement isn’t sustained, nor are they funded for this type of activity.”

Support coordination practice survey

Ninety-nine registered support coordinators responded to the survey from 1,345 providers invited to participate. They included support coordinators (59%), specialist support coordinators (15%) and team leaders (15%). Over half of respondents had been in the role for over two years.

A significant number surveyed reported they were working with participants in crisis on a daily or weekly basis. Overall, survey results (see Figure 1) suggest most providers were either ‘fairly’ or ‘completely’ confident working with their participant.

Respondents were more confident about:

- Reflecting on what’s working and what needs to change
- Coordinating and maintaining connections with supports
- Negotiating and advocating to receive person-centred care

Survey respondents were less confident around supporting NDIS participants with complex needs to obtain technical advice and guidance. Themes included:

- Navigating and understanding the NDIS system
- Obtaining information from and navigating mainstream services
- Understanding responsibilities of different services
- Inconsistency between services
Availability of funds for required disability supports:
- Can be depleted quickly if crisis occurs
- Access to specialist support services including wait lists and compatibility

Access to community and mainstream supports:
- Lack of options for community support e.g. drug and alcohol support
- Appropriate and affordable accommodation
- Barriers to collaboration between health and disability services

Market thinness:
- Lack of experience with complex needs and distance from required supports

Staff skills and knowledge (including my own):
- Knowing who is responsible for what
- Need for more person-centred approaches
- Limited understanding of mental health needs and inclusion
- Reluctance to engage the complex client in supported decision making and processes

Availability of quality evidence to support planning:
- Difficulties obtaining evidence for homeless participants
- Accessing information held by mainstream services
- Understanding purpose of quality evidence to justify supports requested by the participant

Relationships with community and mainstream supports:
- Maintaining good working relationships with providers when participants have complex presentations

Disability inclusion within support services

Other:
- Organisations monopolising supports; limited support from LAC’s and planners; limited capacity to be flexible in support provision

![Figure 2: Challenges experienced by Support Coordinators when assisting participants in crisis](image-url)
Below, a quote highlights insight into provider difficulty:

“Working with some support providers has challenges in regard to their ability to work with people who have very complex needs. We have experienced difficulties with services not having a person-centred approach, having low skill levels, low understanding of mental health needs, low capacity to be flexible in support provision, poor understanding of inclusion and reluctance to engage the complex client in supported decision making and processes.”

The survey also asked about features of practice when good outcomes are being achieved. From 75 responses the following practices were highlighted:

- Promotion of the rights of people with disability
- Use of trauma informed practice and principles
- Collaborative approaches and wrap around support with each party understanding their role in providing support
- Skilled staff and teams
- Flexibility and responsiveness – disability, mainstream and NDIA
- Key person providing single point of contact
- System navigation capability to receive correct information and access required support
- Being able to access services that they had to wait for in the public system or may not have been able to access if not for the NDIS
- Use of specialist advice and recommendations when needed
- Good engagement with the person and understanding of their individual needs and goals
- Adequate support coordination
- Recognition of good practice

“A client of mine has stayed connected to support services after a meeting was held between the service and the client…there were issues with abusive phone calls and actions towards staff. (Through the) meeting we came up with a plan and the client has worked well with service for a short period, and hopefully well into the future.”

Types of professional development and training priorities that respondents believed would help them be more successful in their role are included in Figures 3 and 4.
Figure 3: Professional Development areas that Support Coordinators believed could enhance their practice

Figure 4: Training priorities

Interestingly, survey respondents indicated that they experienced barriers accessing professional development. Workload and a high percentage of billable hours were the main barriers. For some it was compounded by crisis driven time management and lack of organisational support for training, with some support coordinators forced to undertake training in their personal time. Other barriers can be viewed in Figure 5 below:
<table>
<thead>
<tr>
<th>Barrier</th>
<th>Comments</th>
<th>Response %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time/workload</td>
<td>KPI’s, high % billable hours, crisis driven time management, having to do training in personal time</td>
<td>44%</td>
</tr>
<tr>
<td>Cost/not paid enough</td>
<td>Small organisation, independent support coordinators, hourly rate not enough to fund training</td>
<td>33%</td>
</tr>
<tr>
<td>Distance</td>
<td>No local training, cannot travel to regional centres</td>
<td>10%</td>
</tr>
<tr>
<td>Availability/accessibility</td>
<td>No central area for disability training, no access to clinical supervision</td>
<td>17%</td>
</tr>
<tr>
<td>Quality</td>
<td>Available training too basic, not accredited, no official NDIA training for SSC* and CoS**</td>
<td>13%</td>
</tr>
<tr>
<td>Organisational</td>
<td>Organisational policy and low prioritisation of training</td>
<td>6%</td>
</tr>
<tr>
<td>Other</td>
<td>COVID-19, competition among services</td>
<td>4%</td>
</tr>
<tr>
<td>None/not applicable</td>
<td>No barrier reported</td>
<td>10%</td>
</tr>
</tbody>
</table>

*Specialist Support Coordination; **Coordinator of Supports

**Figure 5:** Barriers to accessing professional development

## Function 2

### Subject Matter Expertise (SME)

#### Consultancy and peer support

The uptake for this service has been significant. Between mid-May and the end of July, the ECSN team responded to 35 referrals. Each consultancy session is recorded (with permission from the referrer) and undertaken virtually. Generally, three to four ECSN team members participate, asking questions and providing initial ideas for referrers to consider. Recording the session has several advantages. It provides staff unable to participate opportunity to view and contribute afterwards and allows the report writer to analyse the conversations in greater depth. The recording is deleted after the report has been finalised.
Following discussion and analysis, a report is prepared with input from the team and then emailed to the referrer. A post-consultation survey is sent to the support coordinator to enable feedback to be provided about the session. Whilst the consultations and peer support continue, the team have also turned their attention to examine narratives in these consultation reports and will report on themes in the next communication. Additionally, we have begun to reflect on the process and exploring how it may be improved.

**Function 3**

**Crisis response and referral**

**Statistical information for After-Hours Crisis Referrals**

The After-Hours Crisis service is a key component of the ECSN program. The team analysed information from 20 external and internal reports of After-Hours Crisis situations and responses between February 2020 and 12 July 2020.

The majority of crisis referrals (75%) occurred in New South Wales, followed by South Australia (20%) and the Australian Capital Territory (5%). These referrals were initiated only from metropolitan or regional areas. Most referrals were from the NSW Illawarra Shoalhaven Local Health District, followed by Metropolitan Adelaide and Western Sydney (Figure 6). More male (70%) referrals were received and Figure 7 displays some variability between participants ages (18-62 years) requiring crisis response, but most (70%) were aged between 18-42 years.

**Figure 6: Crisis referrals by State, Territory and Local Health District (NSW)**
Below, Figure 8 displays the number of crisis referrals. Data indicates an increase of referrals between February and March, followed by a significant decrease from March to May, coinciding with the first wave of the COVID-19 pandemic. Health and disability authorities predicted an increase of After-Hours referrals due to hospitals having reduced capacity to accept non-urgent admissions. However, this did not occur and authorities suggested that this may be due to hospitals, in their preparation for COVID-19, having a surplus of beds that were not being used due to initial containment of the virus, and were used for disability-related crisis management rather than escalating through appropriate channels.

**Figure 7** Age of crisis referral Participants

**Figure 8:** Number of crisis referrals by month

**Preliminary risk factors for crisis**
From these 20 referrals, similarities between participants characteristics, experiences and living environment are emerging. Over time, with more data, we anticipate being able identify risk factors and other influencing factors that may increase participants likelihood of entering crisis. The themes explored in this section are common factors that are not in themselves crisis situations, but potentially increase risk. Data collected focuses on historical or secondary level information and should be considered as background information.

The majority (70%) of participants when referred, were living in SIL, STA or MTA accommodation facilities. Over half of participants referred (55%) were already receiving high staffing levels of 1:1 ratio or higher. When considering a participant’s support network and current life stage it is important to note that 70% of participants had limited to no informal supports, or informal supports that were not involved in a practical capacity. Half of participants referred through the crisis line had recently experienced or had an upcoming major life transition. Transitions included: moving to a new area, family or informal support breakdown, and changing over from long term supports.

With 20% of referred participants reporting whole of life supports with one or two providers, it is concerning that 45% of all referrals reported concerns with their current supports pre-crisis. Not including the immediate crisis, 35% of referrals reported recurrent poor interactions with mainstream and funded services and 65% of referrals reported recurrent admissions to hospital for non-medical reasons pre-crisis.

The majority of crisis referrals were primarily due to Behaviours of Concern (BoC). Most referrals (80%) reported a pattern or history of behaviours of concern prior to the crisis event. Over half (65%) of the BoC referrals had either insufficient or no behaviour support funding. Participants referred also presented with well-known existing risk factors for crisis including:

- Disengagement from supports or having no supports in place
- Recurrent homelessness or transience
- History of trauma and/or abuse

A weakness of the dataset is that collection of historical information is dependent on ECSN staff (differentiation of knowledge/skills) and knowledge of the referrer. There are currently few parameters for compulsory information gathering points relating to a participant’s background or pre-crisis.

![Figure 9: Primary reason for crisis referral](image-url)
circumstances. However, we believe this is a good practice that has been adopted and important information has emerged from this. We are currently examining ways to improve data collection.

**Contribution factors to crisis referrals**

Despite this modest sample size, themes of why crises occur are emerging. Nevertheless, caution is required as more data is needed to confirm these trends.

Most referrals (70%), see Figure 10, were made following hospital presentations. Nearly all (95%) participants had a cognitive impairment and/or reduced behaviour regulation capacity and (65%) were referred because of behaviours of concern including self-harm, violence towards carers, property damage and physical aggression.

These hospital presentations appear to be an area for further investigation. No participants referred through the After-Hours line were admitted to hospital for medical or health related issues. All presentations were social, behavioural or care was relinquished by service providers, or participants were unable to return to their place of care. In this sample, hospitals appear as a method for extracting participants from their accommodation settings due to carers difficulty managing participant behaviour(s). This could be for a variety of reasons including: staffing ratios, inadequate funding in plan for support needs, no behaviour plans in place or not being used correctly, staff without adequate skills to deal with behaviour and/or accommodation was unsuitable for the participant.

![Figure 10: Approved Referrers Initiating Crisis Referrals](image)
Internal self-evaluation and reflection of the After-Hours process

In reflecting on our delivery of services so far, ECSN staff provided insight into the program’s strengths and areas that required improvement. This information was collected through individual interviews with staff and will support the continual development of the ECSN program.

There were a number of strengths and areas of success identified by team members including:

- Ability to respond to the crisis
- Meeting expectations of stakeholders
- Quality of information collected about crisis prevention points

Individuals reported the team (including its management, skill set, culture and processes) was widely successful. Staff felt well supported and prepared to work in complex situations. Furthermore, the team felt they were responsive to stakeholders and expectations of participants and referrers were well managed. Comments to facilitate a short-term crisis response included:

“\textit{We are empowering stakeholders}” and “\textit{managing our own responses}”

Staff also reported that the information collected through Function 3 of the program is providing information about potential trends in what occurs pre-crisis, as well as some crisis preventative measures that may be used to facilitate systemic change.

While there was a general consensus about the positive outcomes being achieved to date, there were also some areas of improvement identified by ECSN staff. The team identified that they would benefit from clarification of role expectations and role differentiation, particularly in relation to expectations of the team following a crisis call during business hours.

This includes clarifying exit points as well as navigating role expectations with duty of care to participants. The team identified that it would be beneficial if communication between stakeholders increased during business hours (e.g. through the form of a warm handover), as this would provide clarity around the ECSN staff member’s exit point. Moreover, this may facilitate more positive relationships between stakeholders, ensuring a collaborative and informed approach is being implemented to support the participant. The team also identified that they would benefit from having select few after-hours ready providers for efficiency.

Staff identified the following areas of training that may support service delivery:

- How to be the initial receiver of phone calls
- Mental Health Act (2007) training to further understand what constitutes an admission to the mental health ward
- Legal rights training in relation to potential participant accommodation eviction

Our reflection and evaluation processes are and will remain important tools for increased understanding. These will facilitate the continual development of the ECSN team and ensure the continued delivery of high-quality and person-centred practice to participants in crisis.
Conclusion

Initial data collection and analysis has provided important insight into the ECSN program and highlighted early trends which will continue to inform future program improvement and planning.

Based on information collected through the Support Coordinator survey, there are multiple areas of focus that will be addressed through Function 1 of the program moving forward. Participation in and facilitation of quality, cost effective and time efficient knowledge exchange activities that focus on; developing an understanding of the function of support coordination during points of crisis, navigating NDIS and mainstream systems, person centred approaches to working with participants with psychosocial disability, understanding and responding to behaviours of concern, and engaging participants with complex support needs in supported decision making.

We will also seek to address identified barriers to collaboration between mainstream and disability services through facilitating connections between key stakeholders at local levels, and promoting participation in knowledge networks that further enable connection and collaboration between a range of sectors. In order to address barrier to training and professional development, the ECSN program will ensure that strategies delivered under the program are quality, cost and time efficient, while utilising the outcomes from the consultation and peer support process to influence good practice on an individual level. Our relationship with the NDIA can also be utilised to raise reports of market thinness and barriers to training and development identified within the sector.

Work undertaken for Function 2 continues to progress and become more refined. Finalisation of the complex support coordination guide will assist support coordinators to provide best practice approaches when working with participants who have complex support needs. This document will be available to support coordinators across our footprint. The framework prepared by the ECSN Team provides guidance and case studies to increase support coordinator’s ability to work in multi-disciplinary practices, understand intersectionality, identify and respond to crisis, reduce service disengagement and increase their ability to collaborate and engage with government and mainstream services. The consultancy and peer support program will continue to take on new referrals and is currently undergoing evaluation and review to improve information gathering, referral triage and facilitation of consultancy sessions with referrers.

Following staff feedback regarding Function 3, several changes are being made to improve the consistency and service delivery of the After-Hours referral process. Development of guidance resources is currently underway to improve staff confidence in managing After-Hours referrals and provide clear instruction throughout the process to ensure quality service delivery. Identified areas for training and staff skill development have been communicated to management, with some skill building in motivational interviewing planned for the coming months. An on-call management program to manage staff after hours rostering and call triage is currently being examined by the IT department for implementation in the near future, with the aim of improving workflow.

Our overall program objective is continued quality service delivery for participants with exceptionally complex support needs, improving wider sector capability to work in crisis and complexity, and contribute to systemic change more broadly through engaging with stakeholders, gathering valuable information and collaborating with the NDIS.
Acknowledgements

We would like to acknowledge the contribution of participants, the disability sector, support providers, and stakeholders to the continuous improvement of the ECSN program and quality service delivery. We would also like to acknowledge the ECSN team:

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Mel Plant – Administration Officer
Cameron Stott – Specialist Support Coordinator
Quyen Tran – Provisional Psychologist/Positive Behaviour Support Practitioner
Victoria Turner – Positive Behaviour Support Practitioner/Specialist Support Coordinator
Caitlin Wilcox – Provisional Psychologist/Positive Behaviour Support Practitioner
Dean Bright – ECSN Portfolio Manager