Community Options
Serving the Canberra region

Community Assistance and Support Program (CASP)

Background and Referral Sources

The ACT Government Community Assistance and Support Program (CASP) commenced on 1 July 2016. From commencement of the program on 1 July 2016 until the time this report was prepared on 24 November 2017, Community Options received a total of 665 referrals to the CASP program. The vast majority of referrals to the Community Options CASP program came from hospitals, primarily for short-term, episodic support following discharge from hospital. The table below provides a summary of referrals by source to the Community Options CASP program from 1 July 2016 to 24 November 2017. As the data in the table below shows, 70% of all referrals received by Community Options in the period of 1/7/2016-24/11/2017 came from hospitals, Clare Holland House, Home Based Palliative Care Team and other ACT Health services.

Community Options CASP Program: Referral data

Referring Organisation	*# of Referrals*	*% of Total*
Canberra Hospital	253	38%
Calvary Hospital	93	14%
Other Hospitals (Calvary John James Hospital, National Capital Private Hospital and Royal Hospital for Women)	19	3%
Housing ACT	60	9%
Home Based Palliative Care Team	47	7%
Clare Holland House	13	2%
Other Act Health Services including; Belconnen Community Mental Health Team, Gungahlin Mental Health Team, Community Nursing And Community Rehabilitation Team	40	6%
Other Services including; Regional Community Services, Alzheimer's Australia Act, Aids Action Council, St Johns Care And Mental Health Foundation)	133	20%
Self-Referrals By Family Members	7	1%
Total	**665**	**100%**

CASP Target Group: Client Characteristics

Community Options services a diverse group of clients under its CASP program. Generally, the clients who are receiving CASP services from Community Options are those people with health conditions and/or disabilities who are: not eligible for NDIS services; in the process of transitioning to the NDIS; or in receipt of NDIS services but require short-term post hospital support following discharge from

hospital. A significantly large proportion of people supported through the CASP program live alone and the majority of these clients are in the 51 to 64 age group. While the Community Options CASP program has serviced a range of clients whose needs and support requirements have been widely diverse and often unique, five main client groups have emerged during the first year and a half of implementation of the CASP program; namely:

1. Recipients of CASP services in this group are primarily males and some women with undiagnosed mental health issues. People in this client group normally come from lower socio-economic backgrounds, have limited or no family support or contact and are often struggling with government systems and agencies, such as Housing ACT;

2. Recipients of CASP services in this group are people who require longer-term support due to medical conditions, e.g. people who are undergoing cancer treatment;

3. Carers of children with disabilities or carers of spouses with chronic health conditions;

4. Clients who require short-term post hospital support, mainly post-surgery or accidents;

5. A range of people waiting for NDIS access; this group also includes people with medical diagnoses made ineligible for NDIS who need to re-apply. Namely:

   a. A new group of clients has emerged during the implementation of the CASP program. This group of clients includes people who have significant impairment or conditions that are permanent and require high level of support on a long-term basis. This group of clients is referred to Community Options (often by hospitals, Clare Holland House or other ACT Health services) for support services through the Community Options CASP program on a short- to medium-term basis while they are awaiting access to the NDIS.

      During 2017, Community Options observed a consistent emerging trend with this particular client group being denied access to the NDIS with their impairment or condition being deemed by NDIA as a "health condition" that is outside of the NDIS scope and the responsibility of the health system. The case studies below (case study #4, 5 and 6) include further information on this client group, their stories and their struggle with the NDIA for access to the scheme.

      Please also note that the analysis of data for current clients (as of mid-February 2018) supported through our CASP program shows that approximately 90 clients have been referred by Community Options to the NDIA for access to the NDIS and only 6 clients (or 7%) have successfully transitioned to the NDIS thus far. Furthermore:

      - 49 out of the 90 clients (or 54%), who have been referred to the NDIS, have been deemed ineligible by the NDIA and as such denied access to the scheme;
      - 14 out of the 90 clients (or 16%) are currently going through the NDIA appeal process;
      - 6 out of the 90 clients (or 7%) are still waiting for a planning meeting following being deemed eligible to the scheme by the NDIA Access Team;

- 27 out of the 90 clients (or 30%) had to submit multiple applications to the NDIA for access to the scheme;
- 10 clients (11%) have been accepted by the NDIA but have not transitioned to the scheme yet.

b. Another distinct cohort within this group is people who are discharged from hospital and who have high level, complex support requirements. These people are often referred by hospital social workers and discharge planners to the Community Options Transitional Support Program (TSP), which is funded by ACT Health to support people across all age groups with high level and complex support requirements following discharge from hospital while they are in the process of transitioning to long-term support arrangements, normally through the NDIS or Commonwealth Home Care Packages Program (HCP). Community Options' TSP program is funded by ACT Health to facilitate discharge of people with complex needs from hospital through provision of in-home support and case management during the transitional period. Support through this program can be provided on a medium-term basis, normally up to 12 weeks.

Recently, Community Options has observed a consistent trend of significant delays in TSP clients' transition to the NDIS resulting in clients requiring access to services for significantly longer than 12 weeks of support that can be offered through the TSP program. It has been observed that delays in access to the NDIS placed a significant pressure on the Community Options TSP program. As a result of these delays, following the completion of the 12 weeks of support under the TSP Program, clients are often extended support under the same program or referred to the CASP program within Community Options or to other CASP service providers in the ACT to ensure there is no disruption in support services to clients following discharge from hospitals until their transition to the NDIS. Case study # 7 tells the story of a client in this particular group and sheds more light on the issues faced by this cohort of clients.

Community Options CASP Program: Client Age Groups

Age Group	*# of clients*	*% of total*
1 to 5 years	0	0%
6 to 11 years	0	0%
12 to 20 years	9	1%
21 to 35 years	85	13%
36 to 50 years	186	28%
51 to 64 years	385	58%
65+	0	0%

CASP Clients: Demographic Information

Category	*# of clients*	*% of total*
Clients who lived alone	*262*	*40%*
Clients from CALD Background	*39*	*6%*
Clients from ATSI Background	*20*	*3%*

Types of Services Provided by Community Options under the CASP Program

Types, duration and frequency of support services are determined on the basis of the individual client needs and circumstances. As such, there is a great variance in the support services received by individual clients. However, common service types emerge and include the following:

Case management – a collaborative service delivery approach that includes active assistance provided to the client with navigation of various systems and government processes and planning and delivery of suite of services in accordance with the assessed needs and wishes of the client; this service through the CASP program often includes assistance provided to clients with transition to long-term service options;

Personal care – standby assistance which includes prompting and encouragement or full assistance with showering bed baths;

Social support – support with accessing activities or groups, shopping, encouraging /supporting use of computers for grocery shopping online;

Meal preparation – meals on wheels or support in learning to prepare and cook basic meals

Domestic assistance– skill building for people who demonstrate behaviours often described as 'compulsive hoarding' or who are living in what is referred as 'severe domestic squalor' situations;

Home modifications – basic home modification services, such as ramps, to improve and maintain people's independence in their homes;

Transport – taxi vouchers, support with transport to appointments where workers stay with the client during the appointment.

***Other* services** – purchase of basic household items e.g. whitegoods and other basic equipment.

Case Studies

Case studies below provide additional information on the nature and scope of services provided through the Community Options CASP program. The case studies also provide an understanding of the client groups, types of interventions and outcomes achieved for clients through the Community Options CASP program. The case studies # 4, 5 and 6 are particularly noteworthy as they tell the stories of the new client group within the CASP program (the client group #6 described above) who have been denied access to the NDIS on the basis of being deemed ineligible by NDIA due to their impairment or condition being deemed by NDIA primarily originating from a "health condition" that is the responsibility of the health system and outside of the NDIS scope.

Case Study #1

Mr M is a 33-year-old man living in a Housing ACT property who was referred to Community Options for assistance with access to and navigation of the National Disability Insurance Scheme (NDIS) and upkeep of property. Mr M is indigenous, identifies as LGBTIQ and has very limited family contact due to past history of child abuse and his sexuality. His mother lives interstate and has sporadic contact with Mr M. Mr M has mental health issues – anxiety, depression and post traumatic symptoms. Mr M also has a history of drug and alcohol abuse, and a chronic heart condition.

While Mr M appeared to be physically independent with all Activities of Daily Living (ADLs), he did not display socially appropriate behaviours or any sign of being intellectually or emotionally interested in keeping his home in a reasonably acceptable condition.

Initially, Mr M was very hard to engage. Mr M was often not at home for services and was very difficult to contact. The client agreed to liaison through Winnunga Nimmityjah Aboriginal Health Service (AHS) but this proved ineffective.

Mr M was changing his mobile number multiple times and was unable to be contacted unless he rang through with the new number. This was related to buying new SIM cards for $10 which had a bonus $30 credit on them.

Mr M disengaged with Winnunga Nimmityjah Aboriginal Health Service (AHS) and is currently being supported by CAHMA – Canberra Alliance for Harm Minimisation. CAHMA is a peer-based drug user group, run by and for people who use, or have used, drugs. Mr M was visiting daily and staying all day. CAHMA contacted Community Options with client's consent to look at support with different social activities to change his focus from CAHMA to something else. Mr M had been drug free for five weeks by that time.

A meeting was arranged with Vinnies Belconnen – St Vincent de Paul Society for Mr M to be interviewed for a volunteering position. Community Options provided support through the CASP program for Mr M to attend the meeting. The support included direction and suggestions for dressing appropriately, grooming prompts, timing and coaching regarding questions, etc.

Services through Community Options CASP also include weekly support with cleaning tasks. The aim of weekly support is for Mr M to work with the support worker to complete tasks, develop routines

and build skills around managing own home. In addition, a $100 phone credit was provided to the client to enable better communication.

Outcomes achieved so far: Mr M has maintained his volunteering position two days per week. There have been no reports of drug use. Mr M is at home for service and is engaged in support with cleaning. More frequent communication from client has also been noted. Mr M has a new GP who has provided medical information for the NDIS application. The NDIS application has been lodged.

Further goals: Mr M identified wanting to have a purpose and a reason to get up each morning. As such, further goals include looking at other options for social activities or volunteering.

Case Study #2

Mr D is a 43-year-old man living alone in a Housing ACT two bedroom townhouse. Mr D has recently relocated to this property following the demolition of Housing ACT properties in the inner city. Mr D was referred to Community Options by Housing ACT. At the time of acceptance to Community Options CASP services, Mr D identified two main goals he wanted to work towards: maintaining his tenancy and "to be like his brothers," which was to have social contacts and activities appropriate for age and to gain employment.

Mr D has an undiagnosed mental health condition following a psychotic episode in his early twenties which resulted in his hospitalisation. He has a history of hoarding and obsessive compulsive behaviour. He is reliant on his family for support and has no other social contacts. Engaging with Mr D has been somewhat difficult. He tends not to answer his phone or his door to anyone other than his family. Mr D's mother advised they also experienced difficulties with contacting Mr D.

Mr D is in receipt of the Newstart Allowance. He has been receiving the Newstart allowance for the past ten years. According to his mother, every fortnight Mr D applies for the required number of jobs to maintain his payment but has not been successful in securing a full-time position. This arrangement took up most of his time and also had a demoralising impact as reported by both the client and his mother. Mr D has had several positions, mainly casual in the hospitality sector, but none over the last couple of years. Both he and his mother reported he was unable to continue with this due to the high level of stress he experienced.

Mr D did not have a regular GP. His mother advised they had not pursued a diagnosis or engagement with Centrelink since an attempt approximately five years ago. Mr D's mother presented as very wary of service and she did admit that she found it all too difficult. Her former husband also had significant mental health issues.

It was agreed at the initial meeting that Community Options would assist with cleaning tasks and social support to assist with engagement in his local community. Namely, the assistance would be structured around Mr D building skills to maintain property and connect socially in his new community. Mr D has different interests such as archery that the formal support could assist to link in with. During the original assessment, it was also discussed and agreed to that Mr D and his mother would engage with a GP locally to explore getting a formal diagnosis and treatment for his mental health condition. Finally, it was agreed that Community Options would provide support with applying for the Disability Support Pension (DSP) and subsequently an application for the NDIS. The

plan was to attempt to change the focus and the purpose of Mr D's life with the option of gaining a supported employment in the future under the NDIS.

Service response from Community Options through its CASP program includes twice weekly support with housework. As part of this assistance, the workers encourage and assist Mr D with housework and paperwork (trying to minimise his tendency to hoard). The workers also assist him to attend social groups and any appointments he may have with the Tuggeranong Mental Health Team as the GP referred the client to ACT Health Community Mental Health for a specialist diagnosis. The client is also currently trialling a new medication with a noted side effect of increased appetite. The provided support also includes basic assistance with meal preparation. The support workers who are assisting Mr D are two male support workers with similar social interests to what the client identified.

Communication with the client is handled by mail or though the client's mother, whenever urgent. Contact with the mother is minimised due to her stress levels and her identification of being overwhelmed with having to do it by herself. A basic support calendar was also introduced as a prompt for Mr D with appointments and services.

Case Study #3

Mr B is a 36-year-old man who lives with his partner Ms J. Mr B has a significant intellectual impairment and Attention Deficit Hyperactivity Disorder (ADHD) as diagnosed by his treating Psychologist. Mr B's Intellectual impairment is also accompanied by a behaviour disorder that triggers angry outbursts often directed at people and support staff around him. Mr B was referred to Community Options by Housing ACT with the aim for Community Options to work with Mr B and Ms J to improve their living conditions and quality of life, upskill Mr and Mrs B with managing daily living tasks and to assist Mr B to transition to the NDIS.

Mr B and Ms J have lived in their current Housing ACT property for the past 9 years without any formal supports. Mr B has no relationship with his father and a very difficult relationship with his brother. Ms J has no relationship with her family or community due to her relationship with Mr B. Mr B and Ms J rely on each other as their informal supports.

Community Options received a referral from Housing ACT to provide a major cleaning assistance to Mr and Ms J. The initial assessment conducted by Community Options revealed that Mr B and Ms J had two dogs in their home. The assessment also showed that Mr B and Mrs J did not have any skills or even an understanding of how or why the house needed to be cleaned and maintained.

Community Options provided assistance with cleaning. This assistance was provided by two staff members twice a week. This service started with support staff assisting Mr B and Ms J with the removal of rubbish and any other items that did not work or needed to be discarded of. This service took a period of three months to complete.

Following the removal of rubbish, the service focused on teaching Mr B and Ms J the skills required to maintain their property. The support staff worked with Mr and Ms J to teach them how to complete the daily living tasks, such as removing the dog faeces from the floor with gloves and a bag and putting these in the bin. Prior to learning this, Mr B used a shovel to pick the faeces up and throw out the back door. After a period of three months Mr B and Ms J were completing tasks of

daily living independently. Support workers would arrive for the services to find out that the clients have already completed these tasks. As a result, Community Options reduced the services to once a week as a way to make sure the house was kept in a healthy state. Community Options has also provided assistance with an application to the NDIS. Currently, Mr B is awaiting confirmation of his acceptance into the Scheme.

Case Study #4

Mrs P is a 58-year-old lady referred to Community Options by a social worker from the National Capital Private Hospital (NCPH). In March 2017, Mrs P was diagnosed with Glioblastoma Multiforme (GBM), an aggressive brain cancer. Prior to the diagnosis, Mrs P lived in Tasmania and had been experiencing symptoms of GBM for approximately 15 months. Mrs P's condition was initially misdiagnosed as possible epilepsy in Tasmania. The client's daughter, who is a General Practitioner (GP) in Canberra, brought her mother to stay with her for further investigations which subsequently resulted in the diagnosis of GBM and debulking of tumour at the NCPH. During the surgery, Mrs P sustained a stroke resulting in the weakness in the left lower limb and complete loss of function in the left arm. As a result, the client required full assistance with all activities of daily living. The client's personal care support required assistance of two workers. The client had all required equipment in place including commode, wheelchair, ramp, hospital bed and Steady Eddy.

In May 2017, Mrs P was discharged to her daughter's home in Canberra. The client's husband took leave from work to stay in Canberra to assist with Mrs P's care. The hospital social worker made a referral to Community Options for support following discharge from hospital. The hospital social worker also submitted an application to the NDIA for long-term support under the NDIS. Community Options' support through the CASP program included personal care (showering) assistance provided by two support workers five times per week. Client was initially reluctant to have any formal support but eventually agreed to accept it. The provided support eased some pressure for the family and allowed the family to assist with all other supports.

The application for the NDIS was made in May 2017. In October 2017 five months after the lodgement of the application to the NDIA, the client's daughter requested Community Options to increase support to 10 hours per day four times per week commencing from January 2018. The increased support was required due to the client's husband needing to return to Tasmania to maintain his employment and mortgage repayments. The requested support would also allow the client's daughter to continue her employment as a GP four days per week, Mondays to Thursdays. The estimated cost of the requested support was approximately $2,500 per week which included the cost of two support workers required for assistance with showering. A discussion was held with the daughter to explain how the requested level of support was technically out of scope of the CASP program and the need to progress with the application to the NDIS for funding assistance to cover longer-term, high-level support needs. It was agreed that Community Options would provide the requested support for a short period of time and that the daughter would advocate with the NDIA to provide funding for the level of support Mrs P required in the longer-term and given the significant change in their family circumstances.

In November 2017, Mrs P's daughter contacted Community Options very distressed stating that the NDIA deemed Mrs P ineligible for the NDIS due to her impairment being primarily due to her health

condition (cancer) and thus being out of scope of the NDIS and the responsibility of the health system. According to Mrs P's daughter, the exact words used by the NDIA when the rejection of her mother's NDIS application was discussed were: "cancer is a disease, not a disability." On this basis, the client's NDIS application was rejected. Mrs P's daughter reported that she felt disillusioned by the system and felt like she had lost a battle. Mrs P's daughter also stated that she had commenced the process of appealing the NDIA's decision.

In December 2017, the client's daughter contacted Community Options to advise that a recent Magnetic Resonance Imaging (MRI) scan showed a significant regrowth in tumours and poor prognosis for Mrs P's life expectancy. Given this development in the client's condition, the family decided not to proceed with the NDIS appeal process and the client's husband would stay in Canberra to continue to care for his wife. Mrs P died on the New Year's Eve in her own home.

Case Study #5

Mr M is a 47-year-old man who lives with his wife and their under-school-age child. Mr M was referred to Community Options by a social worker from the Cancer Counselling Service following his discharge from a hospital in Sydney after an extensive posterior and pelvic surgery. The surgery resulted in removal of all organs from his pelvic cavity. Following the surgery, the client spent two months in hospital. Mr M also had a previous surgery in 2013 for rectal cancer following which he underwent a chemotherapy treatment. In October 2017, he had further surgery to correct a fistula which had previously required daily dressings by community nurses (ACT Health Community Care Program: Community Nursing and Community Care Allied Health Services).

Mr M cannot be left alone for any longer than 1 to 2 hours due to high falls risk as a result of the chronic nerve damage post-surgery and frequent leakage from stomas requiring assistance with the baseplate, clean up and personal care. The client also requires daily assistance with stoma care as he is unable to manage one of the stomas due to placement and distortion of abdomen from previous surgery. ACT Health community nurses attend to this. Mr M is unable to walk more than 30 metres without assistance. He uses a walking stick around the home and a wheelchair for community access. The client also has strict nutritional intake needs requiring separate meal preparation.

Following the surgery, Mr M was able to retain his job by working from home part-time. One of the bedrooms was converted into a study to allow Mr M to work from home. Mrs M, the client's wife, also works part-time to help with their family finances and significant costs associated with paying off their home mortgage, extensive medical bills, and day-to-day living expenses.

Community Options arranged in-home support for Mr M and his family. Initially, support through the Community Options CASP program included four hours of service per week. This support included assistance with domestic tasks to provide some assistance to the client and his wife who was and continues to be under a considerable carer stress. Mr M's father and mother who live interstate have also provided support to the family. Since May 2017, the client's parents have been coming to Canberra to provide support to the family. Mr M's parents have been staying with the family three days per week while Mrs M, the client's wife, is at work. Mr M's parents described the daily routine and the assistance they were providing to the family during the day which included a two hour morning routine for Mr M. The morning routine involved replacing Mr M's kylies, helping change his

stoma plate, emptying his water stoma and cooking him breakfast separately due to his strict dietary requirements. Mr M's parents also reported that Mr M's daily routine required considerably significant efforts and assistance particularly when getting him in and out of bed in the morning and at night and assisting with getting to specialist medical appointments and various scans. In addition, Mr M's parents reported that due to frequent falls and the stoma baseplate often coming adrift, somebody had to be in the house most of the time thus not being able to leave Mr M alone at home.

To take some of the pressure away for the family, Community Options increased services through the CASP program from four hours per week to eighteen hours per week as an interim measure until the client can access the NDIS. The increased support includes four and a half hours of service per day four days per week. This support has enabled Mr M's parents to take in turns coming to Canberra each week to continue to support the family, leaving Monday mornings and returning Wednesdays in the afternoon. The parents had also been paying privately for Kylies to be laundered and for garden maintenance. Community Options' support under the CASP program now also includes workers assisting with washing the Kylies. Community Options also referred the family to another service provider for Government-funded garden maintenance service.

Mr M has recently been denied access to the NDIS. The NDIA found Mr M ineligible for the NDIS due to his disability being primarily due to his health condition (a diagnosis of cancer) and thus being out of scope of the NDIS and the responsibility of the health system. Mr M is currently appealing the NDIA's decision.

Case Study #6

Master DC was referred to Community Options by the Home Based Palliative Care Team, Clare Holland House, in March 2016. At the time of referral to Community Options, DC was a 9-months-old baby boy diagnosed with Hypoplastic Left Heart Syndrome (HLHS) – a congenital heart defect that affects the formation of the chambers of the heart. DC's condition was considered palliative upon birth. The initial prognosis for the baby boy was very poor with DC not being expected to make the ambulance trip from Sydney to home in Canberra. However, later on DC's condition was deemed to be no longer palliative but chronic with the baby needing to grow, build his immune system and be assessed for any possible interventional surgery. DC underwent multiple surgeries since his birth. Following one of the surgeries, he developed a clot in his heart which broke up and caused damage throughout his body. DC also had a stroke to two regions of the brain, non-functioning left kidney, opiate dependency, hypothyroidism and left-sided severe hearing loss. The baby was fed through a nasogastric tube as he had never established independent eating whilst in hospital.

The Home Based Palliative Care Team referred DC and his family to Community Options for in-home respite services including domestic assistance for the mother who was the primary caregiver and to take some pressure away for the family. At the same time, an application was made to the NDIA for support under the NDIS in the longer-term perspective. In June 2016, DC obtained his first NDIS plan. While in-home respite services had been requested through the NDIS, the initial plan had no funding for any services. On appeal the plan included funding for therapies for DC thus not meeting the needs of the family, due to his round the clock care needs. The NDIA refused the family access to in-home respite or services stating that these were "normal parental responsibilities" and thus "outside of the NDIS scope." With the assistance from the social worker at the Clare Holland House, the

family commenced the appeal process with the NDIA. In the meantime, in-home respite services were provided by Community Options, initially through its ACT Health-funded Flexible Family Support Program (FFS).

In September 2016, the baby's mother contacted Community Options stating that she had appealed the NDIA's decision to the Administrative Appeals Tribunal (AAT); however, the appeal was rejected. Namely, Mrs C's appeal for inclusion of in-home respite services in her son's NDIS plan was rejected with the same stated reason—the requested services were what a parent was "reasonably expected" as part of their "normal parental responsibility" and thus "outside of the scope of the NDIS." Mrs C, the baby's mother, was particularly concerned about the rejection of her appeal as she had been offered a part-time job to work as a specialist allied health practitioner. Mrs C had accepted the job offer hoping that the inclusion of in-home respite services in her son's NDIS plan would allow her to work two days per week starting from March 2017. With this plan, it was intended that an in-home support worker would provide the required care for her son while she was at work. Please note that due to very high care needs and very high infection risk, Master DC was unable to access either mainstream or even specialised child care for chronically sick babies and children in the ACT. In addition, the mother was unable to access the Commonwealth Government subsidies for child care in her home as these are not available for in home care for a child in their own home. The family was also required to have a qualified childcare worker sourced and provided for DC's care needs, and the home had to meet guidelines in line with establishing a family day care service. As such, in-home respite service through the NDIS was the only option available to the family. Following the AAT rejection, Mrs C decided to pursue a further course of action which involved legal assistance.

Due to Mrs C being in a desperate situation with no other service option available, Community Options agreed to assist with in-home support on a short-term basis until the finalisation of the appeal process to allow the mother to commence in her new job in March 2017. Due to the significant increase in the cost of support (approximate cost of in-home respite service for 2 days per week 10 hours per day is $1,100) to be provided to the family as a result of this agreement, the client was referred and accepted under the Community Options CASP program. It was explained to the mother that this level of support could be provided through the Community Options CASP program only on a short-term basis. Please also note that Mrs C has agreed to make a contribution of $100 per week, which is roughly an equivalent of what parents' out-of-pocket expenses are for mainstream childcare for two days per week. At present they are still not entitled to any further Commonwealth or State based childcare (Childcare Rebate or Childcare Benefit) support to assist with this arrangement, both of which they could access when their other child attended mainstream care.

The setup of the in-home respite services for the family also involved considerable case management efforts. Namely, sourcing a reliable and appropriately skilled in-home support worker who would be able to provide an appropriate care safely to DC involved significant efforts due to DC's high care needs that required a certain level of clinical training. Lengthy discussions with a number of Community Options brokerage agencies revealed that the level of clinical skill that was required for delivery of care to DC could not be sourced within the community care workforce whose highest level of qualification is Certificate III or IV in Aged Care and/or Disability Services.

After a few weeks of search of an appropriately skilled worker, the mother contacted Community Options suggesting that a person she knows well through her local community is able and agreeable to provide the care she requires for her son. Community Options was able to connect the suggested person with one of its registered brokerage agencies. Once the initial recruitment and induction process with the brokerage agency was completed, the worker was able to commence providing the care to DC as part of in-home respite support to his mother two days per week. This arrangement has worked successfully for more than a year now.

In December 2017, Mrs C contacted Community Options stating that she had sought legal assistance for this matter and was now supported by a barrister from the Legal Aid ACT and that her case had become a legal matter handled in the court. According to Mrs C, her case is particularly complex suggesting that the NDIA potentially did not want to set a precedent by funding support for a mother of a child that is considered by the NDIA as a "normal parental responsibility." Community Options is continuing to provide support to this family while the matter is being handled by lawyers.

Conclusion

As the data and the case studies provided above in this report demonstrate, demand for services under the CASP program and other ACT Health-funded programs of Community Options has increased dramatically since the commencement of the program on 1 July 2015 putting increased pressure on these programs. A number of distinct client groups have emerged (please refer to the client groups described in the CASP Target Group: Client Characteristics above). Consideration should be given to an emerging trend with clients with various health conditions being denied access to the NDIS and the resource impact of this alarming trend on the CASP and other ACT Health-funded programs.