



Standing Committee
Health, Ageing and Social Services
ACT Legislative Assembly

Dear Committee Members,

Re: Inquiry into the Implementation, Performance and Governance of the National Disability Insurance Scheme (NDIS) in the ACT

We appreciate an opportunity to make a submission to the Standing Committee's inquiry into the performance of the National Disability Insurance Scheme in the ACT. We trust that this submission provides some insight and information for the Standing Committee in relation to this inquiry and highlights issues that ACT residents face in relation to accessing suitable and timely supports from the NDIS.

We would also like to thank you for your consideration of information provided in this submission and would like to welcome the Standing Committee's very timely inquiry into the matter of the National Disability Insurance Scheme's performance. We would also like to offer our full cooperation to the Standing Committee in this inquiry. As such, would welcome the opportunity to provide further information or answer any questions the Standing Committee may have in relation to this submission.

Should you have any questions in relation to this inquiry or would like to receive additional information, please do not hesitate to contact me on (02) 6295 8800 or at brian.corley@communityoptions.com.au.

Yours faithfully,

Brian Corley
Chief Executive Officer



Community Options

Serving the Canberra region

**ACT Legislative Assembly Standing Committee on Health, Ageing
and Social Services: Inquiry into the Implementation, Performance
and Governance of the National Disability Insurance Scheme (NDIS)
in the ACT**

Community Options Submission

29 March 2018

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List of Acronyms

- AAT – Administrative Appeals Tribunal
ADL – Activities of Daily Living
CABA – Centre for Applied Behaviour Analysis
CASP – Community Assistance and Support Program
FFS –Flexible Family Support Program
GBM - Glioblastoma Multiforme
GP – General Practitioner
HLHS – Hypoplastic Left Heart Syndrome
ISPs – Disability ACT funded Individual Support Packages
LAC – Local Area Coordinator
MRI – Magnetic Resonance Imaging
NCPH – National Capital Private Hospital
NESB – Non-English Speaking Background
NDIA – National Disability Insurance Agency
NDIS – National Disability Insurance Scheme
TCH – The Canberra Hospital
TSP – Transitional Support Program

1. Introduction

The Standing Committee on Health, Ageing and Social Services of the ACT Legislative Assembly (the Standing Committee) resolved to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT with the particular reference to a number of issues, amongst them: "(a) the relationship between the ACT Government and Australian Government in regard NDIS and National Disability Insurance Agency (NDIA)." As a provider of disability and community support services under the NDIS and ACT Government-funded programs and services, Community Options is pleased to forward this submission. We trust that this submission provides some insight and information into the Standing Committee's inquiry above and highlights some of the issues we have observed relating to the implementation of the NDIS in the ACT: (1) quality of planning processes particularly as it relates to timeframes and inconsistency of outcomes for NDIS participants; (2) an increasing trend of institutionalisation of people with disabilities who have high support needs yet they had lived successfully in the community for many years prior to transitioning to the NDIS; (3) lack of recognition of support coordination as an essential service type by the NDIA; (4) lack of engagement with providers by the NDIA.

2. About Community Options and its role under the National Disability Insurance Scheme

Community Options is a not-for-profit provider of aged care, disability and community support services in the ACT. We have been providing services to ACT residents for the past twenty-eight years. Community Options specialises in provision of: (1) case management, in-home and community based support services for people with complex support needs and social circumstances; and (2) provision of post hospital support services to ACT residents. Under the NDIS, Community Options provides support coordination and plan management services. These include:

- Purchasing services under the NDIS Plan;
- Assisting NDIS participants with implementing their NDIS Plans including finding the most appropriate providers of supports and negotiating service arrangements on their behalf with the identified direct service providers;
- Developing service agreements for purchasing supports under the NDIS Plans;
- Monitoring and coordinating support services purchased under the NDIS Plans;
- Assistance with budgeting and planning including setting up claiming arrangements for individual support items with direct service providers;
- Assistance with navigation of mainstream health and human services systems including assistance with linking to services provided through other government systems;
- Trouble-shooting assistance including assistance with resolving any issues that may arise during the implementation of the NDIS Plan.

Community Options has been a registered NDIS provider of support coordination and plan management services since the introduction of the NDIS in the ACT on 1 July 2015. Since the NDIS introduction, Community Options has provided coordination and plan management services to 187 NDIS participants. Prior to the NDIS, Community Options had provided services to people with

disabilities and their family members under a number of ACT Government funded programs including the Disability ACT funded Individual Support Packages (ISPs). During the implementation of the NDIS in the ACT, as an organisation we have seen many ACT residents we support transition from the ACT Government-funded services to the NDIS. As a provider of support coordination and plan management services to people with complex support needs, we have gained firsthand knowledge and experience of issues many ACT residents are facing when accessing support under the NDIS. The information included in this submission highlight some of these issues. The case studies included below in this submission are particularly noteworthy as they tell the stories of some of the ACT residents that we have supported under the NDIS.

3. Issues with the Implementation of the NDIS in the ACT

3.1 Issues with Quality of Planning

In the course of provision of coordination services under the NDIS, Community Options has supported many ACT residents in their transition to the NDIS. This often involved active assistance with collecting paperwork required to demonstrate eligibility for gaining access to the NDIS as well as supporting clients as they go through the planning processes. We have seen many people with significant disabilities experiencing a number of issues, including:

- Inadequate timeframes for being assessed for eligibility and for planning processes to occur causing significant delays in ACT residents' access to essential support services under the NDIS*

Many ACT residents we have supported under the NDIS or through ACT Government-funded programs have experienced significant delays in accessing the NDIS for essential services. Some of them had to wait for as long as seven months or longer from the date their application was originally lodged with the NDIA to the date their NDIS plan was finalised. We have also heard many people we support being told by NDIA the approximate timeframe for determining the eligibility and for establishing the NDIS Plan to be 12-14 months currently. A significantly large number of people we support have also been made ineligible by the NDIA and have had to go through appeals processes, which further delayed their access to the scheme. The impact of these delays and inadequate timeframes for eligibility and access to the scheme is further described in the Community Options' submission to the ACT Legislative Assembly's Inquiry into the Sustainability of Health Funding in the ACT. Some of the client stories we have shared in that submission have also been included in the Section 5. Case Studies of this submission.

- People being made ineligible for NDIS as a result of plan reviews*

Community Options has also observed a trend with a number of clients who accessed the NDIS in the first or second year of its implementation being denied access to the scheme on the basis of being deemed ineligible in the second or third iteration of the NDIS plans following their plan reviews. This is an alarming trend as a number of these clients have significant impairments and long-term conditions resulting in high level support needs that cannot be met within the ACT Government funded programs and services, such as the Community Assistance and Support Program

(CASP). Alarmingly, a number of these people have been made ineligible due to their impairment originating primarily from a health condition and as such deemed by the NDIA as the responsibility of the ACT Government and the health system. Yet, the disability requirements for access to the NDIS as stipulated by the NDIA primarily relate to having an impairment or condition that is likely to be permanent (i.e. it is likely to be life-long) and the impairment substantially reduces the person's ability to participate effectively in activities, or perform tasks or actions without assistance and support through the scheme.

- *Inconsistency of outcomes*

Throughout our experience as a registered NDIS provider of coordination of supports and plan management services, we have observed significant inconsistencies of outcomes for individual clients as it relates to equity of resource allocation. Anecdotally, we had reports from clients being told by the NDIA planners about plans being devised on the basis of availability of funds at particular periods of time rather than in accordance to the actual needs of the person. Having questioned the former ACT Office of the NDIA during the early days of the NDIS about the mechanisms the NDIA has in place about monitoring the outcomes to ensure equity in access to services under the NDIS, we were advised no such mechanism was in place and the allocation of funds under the NDIS Plan was not subject to any form of moderation. In absence of monitoring and moderation measures, we have seen massive inconsistencies and inequities in access to services under the NDIS since its introduction on 1 July 2015.

- *Lack of Engagement and Communication with the NDIA*

Through our experience delivering services under the NDIS, we have consistently experienced issues with communication with the NDIA particularly as it relates to negotiating clients' individual plans and plan reviews. More often than not, as plan coordinators we initiate urgent plan reviews; however, there is no response from the NDIA irrespective of the urgency of the review request. Very often, this means clients are unable to access essential services due to a lack of response or delays in response from the NDIA.

3.2 Institutionalisation Trend

A trend we have noticed during the last three years of the NDIS implementation in the ACT is institutionalisation of people with high support needs. Namely, a significant number of clients we have supported have been denied access to the level of support they required under the NDIS to be able to continue to live independently in their own homes. Many of these people were left with the only choice of having to move to a group home as the supported independent living was the only service option offered by the NDIA, contrary to their expressed wishes and best interests. Yet, the same people had lived successfully in the community for many years prior to introduction of the NDIS. This is a particularly alarming trend we have observed during the last three years as it will most likely lead to further re-institutionalisation of people with disabilities.

3.3 Support Coordination

Support coordination service under the NDIS has been a bone of contention from the very beginning of the introduction of the NDIS as a trial in the ACT. Unfortunately, it remains to be contentious to

date with little or no recognition given by NDIA to the importance of this service for successful implementation of the overall plan, particularly for those people who have significant physical and intellectual impairment and who often experience heightened social vulnerability and disadvantage. People belonging to this distinct target group often require the support coordination service due to a lack of capacity to implement their plans and require this service on an ongoing basis. Yet, as some of the case studies below demonstrate (Case Studies 5,6,7,8 &9 in particular), support coordination is either consistently underfunded or do not receive any funding at all past the first year in many of our clients' NDIS Plans. While little or no explanation is often offered by NDIA to explain and justify the level of support coordination approved in NDIS Plans or the rationale behind cancelling the support coordination in the second or third reiterations of people's NDIS Plans; it is often implied by the NDIA that funding for support coordination under the NDIS is only a temporary measure given to NDIS participants in their first plan with an expectation that they would build capacity to coordinate and manage their NDIS Plans in subsequent years. This expectation is often unfulfillable and dangerous in the case of many vulnerable and socially disadvantaged NDIS participants for whom support coordination is a vital service that serves as an essential safeguard and is required on an ongoing basis.

4. Case Studies

Case Study #1

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 ACT Government-funded Community Assistance and Support Program (CASP) 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 #2

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 one to two 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 thirty 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 (ACT Government funded) 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 #3

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 (ACT Government funded). 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.

Case Study #4

Mrs AC is a 38-year-old lady referred to the Community Options Transitional Support Program (TSP, a post hospital support program funded by ACT Health) by the Canberra Hospital (TCH) in July 2017 following an admission in May 2017 for debulking of a sphenoid wing meningioma. Mrs C lives with her husband and their two children: 12-year-old and 3-year-old sons. Mrs C was diagnosed with a slow growing brain tumour with previous surgeries resulting in the loss of vision in her right eye. The surgeries also resulted in Mrs C being very impulsive, suffering from a short-term memory loss, loss of ability to make new memories, disturbances in gait and balance. Mrs C is prone to falls and requires one-on-one supervision for all mobility. Due to fast speech, soft vocalisation with reduced

range of movement of lips, tongue, and limited articulation complemented with the client being from a Non-English Speaking Background (NESB), Mrs C is very hard to understand.

During the admission in May 2017 leading to the referral to the Community Options TSP program, a third application was submitted to the NDIA for access to the NDIS. The previous two applications had been lost by the NDIA. Mrs C requires supervision 24 hours per day and intensive assistance with all personal and social activities of daily living, such as assistance with physically eating and drinking, and monitoring due to impulsive behaviours. For example, the client may turn on hot water only to wash her hands, etc. The client is also a high risk of falls. The client has some equipment in place including a wheelchair, bed monitor and shower chair.

Following a lengthy discussion with the client's husband on the key priority areas of support the family required upon discharge from hospital until their anticipated transition to the NDIS, a support plan through the Community Options TSP program was set up in July 2017. This support included in-home services for the client twice a week from 9:00 a.m. to 1:00 p.m. These services were set up around helping Mrs C to feel connected in her home, engage in everyday tasks with the help of the support worker and to enable the client's husband to have a break and attend to his appointments. Please note that the husband, Mr C, suffers from medical issues of his own requiring multiple medical appointments. Mr C also had a current dispute with Comcare regarding his own benefits and entitlements under the Comcare scheme. Shortly after the commencement of services under the TSP program, the husband reported an increased level of stress in his caring role. Additional services were set up for the family to alleviate some of the pressure for the husband and the family.

Following twelve weeks of support through the Community Options TSP program was completed, the client still had not been granted access to the NDIS. As such, in October 2017 the client was referred and accepted under the Community Options CASP program. Please also note that the client's husband, Mr C was a strong advocate for his wife, e-mailing and calling NDIA regarding his wife's NDIS application every two weeks over this period. Later in October 2017, Mr C contacted Community Options to advise that the NDIA rejected his wife's application on the basis of finding her ineligible for the NDIS. According to the husband, Ms C was denied access to the NDIS for failing to meet section 24 (1)(e) of the NDIS Act which requires that the participant must be likely to require support under the NDIS for their lifetime. Mr C expressed his frustration and disappointment in the system and requested that Community Options extend support while they go through a process of disputing this decision. Community Options has agreed to extend the support under the CASP program (ACT Government funding). At the same time, Mr C commenced the process of e-mailing the NDIA expressing his complete disagreement and frustration with the NDIA's decision. Mr C argued in his e-mails to NDIA that this decision was not based on any medical evidence and was not representative of his wife's condition, actual needs and support requirements. In his e-mail correspondence with the NDIA regarding his dispute of the NDIA's decision, Mr C also copied various high-level officials from the NDIA and ACT Health who he thought would help the cause. As a result of Mr C's efforts and advocacy on behalf of his wife, Mrs C was eventually made eligible for the NDIS with the planning meeting taking further two months to occur. Mrs C's NDIS plan was activated in the second part of January, six months after a referral to Community Options from the Canberra Hospital.

Case Study #5

Mr D is a 55-year-old man who has an acquired brain injury. Mr D lives alone in an ACT Housing property with support twice a day, seven days a week for assistance with activities of daily living (ADL). Mr D had his NDIS plan reviewed by a Local Area Coordinator (LAC) from Feros Care on 11 December 2017 at his home. As a result of the review, Mr D was allocated \$4,200 over two years in his latest NDIS plan for assistance with coordination of his supports, or \$2,100 per year. This level of funding is equivalent to 22 hours of support coordination per year or 25 minutes per week. This level of funding also represents a reduction of more than 50% in support coordination compared to the previous plan.

Mr D has been a client of Community Options for a number of years prior to his transition to the NDIS. As such, Mr D has been receiving assistance from Community Options with coordination of his supports for many years. Mr D is at an extremely high level of risk of social isolation due to limited informal support network available to him. Mr D's primary carer and the only consistent informal support is his elderly mother, Mrs D. Prior to referral to Community Options, Mrs D had been providing all support to Mr D and the reason for referral to Community Options was to introduce formal support services to reduce reliance on his mother for support and assistance with organising the support. During the last 12 months, Mrs D's health had deteriorated significantly. As a result, Mrs D is no longer able to provide the care and support she has historically provided to Mr D. Currently, there is no plan in place for Mr D were his mother no longer be able to provide even the most minimum level of support, such as issues around legal guardianship or financial management.

Mr D receives twice daily support with ADL which is equivalent to more than 40 hours of support per fortnight. Such a high level of support requires a significant level of support coordination including extensive monitoring to ensure timeliness and consistency of daily support. Extensive service monitoring is also required to ensure that the delivered support meets the client's expectations and service requirements particularly that Mr D requires assistance with his medication management.

As stated above, Mr D has been a long term client of Community Options. Over many years supporting Mr D, it has been observed that Mr D is finding it challenging to manage his supports, despite his best efforts. Mr D can become increasingly confused and agitated due to issues with his memory associated with the acquired brain injury. Mrs D has advised she did not believe Mr D would be capable of managing his own supports; even if his everyday support services were provided by a single agency. Mr D also requires assistance with coordination of additional support services at times when he needs to attend appointments as he is unable to independently organise extra support.

Despite the detailed information outlining Mr D's needs, support requirements and specific circumstances being provided to Feros Care and subsequently to the NDIA, support coordination did not receive sufficient level of funding in Mr D's current NDIS Plan and was actually reduced by more than 50% compared to the previous year. In addition, it took significant advocacy efforts to achieve an adequate level of funding for Mr D's core support services for assistance with ADL.

Case Study #6

Mr H is a 64-year-old man whose primary psychosocial disabilities are diagnoses of schizophrenia, bipolar disorder and chronic depression. Mr H also lives with chronic pain in his neck and back due to a car accident approximately twenty years ago. According to Mr H's family, his psychosocial disability was a contributing factor to the accident.

Mr H has compulsive hoarding behaviours and lives in what can be described as a squalor living environment. Mr H receives regular domestic assistance but this service can only cover key areas of his home such as kitchen, bathroom and toilet. Mr H also has a history of refusing services but can reach out to a support coordinator with whom he has an established rapport and is comfortable dealing with in regards to support requests and requirements. Mr H's support coordinator at Community Options often needs to use opportunities to put support in for Mr H while he is willing to accept it.

Mr H self-administers his medication and does not want any support with taking medication. Mr H often consumes excessive amounts of medication such as Valium – Benzodiazepine causing impaired coordination and balance, dizziness, and lethargic and confused appearance.

Due to his diagnoses, Mr H often believes he is in conflict with people; currently, he will not speak to his brother due to the perceived conflict between them. Mr H also appears to have issues with how he perceives time, and will often advise that he has not heard from his support coordinator for weeks but in reality he may have spoken to the coordinator only days before. However, Mr H has been able to maintain regular contact with Community Options including his support coordinator and other staff members in his coordinator's absence. Given Mr H's psychosocial disabilities and social circumstances, this is a significant achievement and vitally important in achieving safe and sustainable service outcomes for Mr H.

Mr H had his NDIS Plan reviewed over the telephone conversation with an LAC from Feros Care on 18 September 2017. Community Options support coordinator first became aware of the review that has taken place when Mr H's sister-in-law contacted him to find out if the telephone review had actually been a scam as Mr H had been vulnerable to phone scams in the past.

Mr H and his family (Mr H's sister and sister-in-law) all expressed their concerns about Mr H's NDIS plan review and the way it was conducted. According to Mr H, early in the plan review the LAC asked him how long he was able to concentrate for. To this question, Mr H replied approximately twenty minutes; yet, the plan review conversation continued for nearly one and a half hours. Mr H expressed his frustration with this as he believed that it was unfair for the review to continue for such a long time as he clearly could not concentrate for the length of time. In addition, Mr H stated that he did not feel encouraged or even given an opportunity to include his current support people in the review process, e.g. his sister or his coordinator at Community Options. Mr H described the LAC conducting his plan review over the phone as "rude" and "aggressive." Mr H stated that the LAC repeatedly cut him off during the review and told him that he needed to hurry up with his answers as she had another appointment to get to. This has caused Mr H a great deal of frustration and disappointment.

According to Mr H, during the review the LAC also mentioned to him that Mr H would not have any contact with Community Options after October 2017. Mr H was greatly distressed about this stating that he had thought Community Options would be with him until he died. Mr D was audibly distressed when he was saying this to his support coordinator at Community Options.

The LAC rang Mr H again the day after the telephone review of his NDIS Plan. According to Mr H, the LAC's tone changed to be being "rude" and "aggressive" after about five minutes of their conversation. Mr H stated that he ended the telephone call by hanging up on the LAC.

Mr H was allocated \$2,100 per year for support coordination in his NDIS plan. This level of funding is equivalent to 22 hours of support coordination per year or 25 minutes per week. As Mr H's complex psychosocial disabilities and social circumstances demonstrate, this level of coordination does not match the intensive and regular service coordination requirements of the client as described above.

Case Study #7

Ms B is a 34-year-old woman who has Down Syndrome with a mild intellectual disability. Mrs B lives with her elderly father who comes from a Culturally and Linguistically Diverse (CALD) Background and also has a significant hearing impairment. Ms B also has a sister who also lives in Canberra, but due to her full-time employment Ms B is unable to assist with the liaison with providers for organising support services for her sister.

Ms B and her family approached Community Options in 2016 to assist with support coordination under Ms B's first NDIS Plan for the period of April 2016 to April 2017. Ms B was allocated \$9,408 in support coordination per year in her NDIS Plan. This is equivalent to 104 hours of support coordination per year or 2 hours per week.

Ms B and her family have had minimal contact with service providers since Ms B's graduation from school. Ms B's family were very confused with the NDIS Plan and required active assistance with sourcing and organising the right support with community access and social activities as well as speech therapy and other therapeutic services for Ms B. Under the original NDIS Plan, Community Options was able to organise community based support and therapeutic services for Ms B thus reducing any unnecessary stress for the family. During the course of the first year, Ms B and her family developed positive, trusting relationship with their support coordinator at Community Options. Successful service arrangements were made for Ms B that matched her goals and support requirements. Very positive outcomes were also achieved for Ms B and her family as a result of the NDIS Plan implementation during the first year.

Ms B's NDIS plan was reviewed in March 2017. The review meeting was attended by Ms B and her sister. As a result of the review, funding for support coordination was reduced from \$9,408 to \$566, which is the reduction of funding for this service by 94%. This level of funding is also equivalent to 6 hours of support coordination per year. Ms B's family were not advised by the NDIA that the support coordination funding would be reduced so dramatically. In fact, no discussion was held regarding the support coordination service with the family or the rationale for reduction of funding for this service following the review. The family were very confused and upset about the reduction of their support

coordination service and did not know as to how to proceed with implementing the NDIS Plan with limited or no assistance from the support coordinator.

Community Options offered the family assistance with making direct service arrangements with service providers delivering Ms B community-based support as well as therapy. However, the family expressed concerns in relations to making direct arrangements stating they were devastated and horrified about the prospect of having to manage Ms B's NDIS Plan without assistance of support coordinator. Given that the family did not feel comfortable about proceeding with the NDIS Plan implementation without the assistance of support coordinator, Community Options suggested that the family contact NDIA with a request of the plan review in relation to the level of support coordination allocated in Ms B's NDIS Plan. In the meantime, Community Options continued providing support coordination to Ms B and her family. The six hours of support coordination allocated in Ms B's NDIS Plan for April 2017-April 2018 was delivered in the first six weeks of the plan implementation. Community Options continued provision of support coordination for the following 11 months with no funding from the NDIA.

During the course of the year, both Ms B's sister and support coordinator at Community Options continued to regularly contact NDIA for an update of the requested review. The plan review was eventually held on 16 March 2018. Community Options submitted a request for support coordination in Ms B's NDIS Plan in support of the family's request. At Ms B's and her family's request, Community Options also attended the NDIS Plan review meeting on 16 March 2018. As a result, the new NDIS Plan was approved with 45 hours of support coordination for the period of March 2018 to March 2019.

Case Study #8

Mr W is a 62-year-old man who comes from a CALD background. Mr W came to Australia at the age of 14. Following graduation from school, Mr W worked in a number of industries including the construction industry. Mr W sustained a spinal fracture in 1984. Following a spinal reconstruction surgery, Mr W was unable to continue working in the construction industry and was granted a disability support pension.

Mr W suffers from chronic back and neck pain, which limits his quality of life. Mr W was also diagnosed with muscular dystrophy which has been progressing rapidly during the past three years. The condition affects Mr W's knees, legs, neck, hands and spine. Currently, Mr W uses a wheelchair for mobility. Mr W also uses an orthopaedic bed, a walking frame, a shower chair and a power recliner.

Mr W lives alone. Mr W got divorced 20 years ago. He has three daughters and a son all living interstate. Mr W has a brother, a sister and parents who all live in Canberra. Mr W used to attend local clubs and used to enjoy meeting new people. However, once his mobility was more compromised, he started to refuse attending social activities and now spends most of his time at home.

Mr W has been a client of Community Options since 2010. Following Mr W's transition to the NDIS in 2015, Community Options continued to provide support coordination services under his NDIS

Plan. As part of support coordination service to Mr W, Community Options organises assistance with gardening, domestic tasks, and shopping and meal preparation. Community Options support coordination services also include: liaison and negotiations with the Housing ACT to facilitate Mr W's relocation into a more suitable property; identifying and sourcing suitable services and equipment to maintain his quality of life; and assistance with attending medical and allied health appointments.

Mr W has recently reported to Community Options that he has experienced a significant decline in his physical function over the last six months. Due to the deteriorating nature of Mr W's condition it is likely that his ability to undertake day-to-day activities will require regular review along with the support required for him to live safe and independently in his home.

Mr W finds it difficult to liaise directly with service providers and greatly benefits from the support coordination under the NDIS. Without the ongoing support coordination service, it is likely for Mr W to disengage from services which will have an unfavourable impact on his capacity to safety and independently live in his home.

The support coordination funding allocated in Mr W's NDIS Plan for 2016-2017 was \$2,100, which was equivalent to approximately 25 minutes of service per week or 22 hours per annum. Following the plan review in 2017, the funding for support coordination was completely removed from Mr W's NDIS Plan for 2017-2018.

Case Study #9

Ms L is a 34-year-old lady, who has microcephaly with accompanying intellectual impairment, speaking and walking difficulties. Ms L comes from a CALD background but has lived in Australia since she was five. Ms L lives with her parents. Ms L does not have any siblings but has some extended family in Canberra.

Ms L attended a special school in Canberra. Ms L has done some volunteer work for short periods of time. Ms L does regular swimming and also participates in Special Olympics swimming. Ms L is quite socially isolated and spends most of her time with her parents. Ms L goes to church every Sunday together with her parents.

Ms L has been an NDIS participant since 2015. As part of her NDIS Plan, Ms L receives a number of services that are structured to assist her to develop basic life skills to improve her community participation. The life skills that Ms L is trying to learn include how to catch a bus, buying groceries, cooking and washing. Ms L also attends arts and crafts groups and receives tutoring for arts, reading, writing and computer skills.

Community Options provides support coordination to Ms L under her NDIS Plan. This includes identifying and sourcing tutoring programs which best meet the client's goals and needs as well as exploring various social activities and service options together with Ms L and her parents. In addition, Community Options arranges and monitors Ms L's support services with community access and participation.

Ms L received \$7,335 per year in support coordination under her NDIS Plan in 2016-2017. In 2017-18, funding for support coordination was reduced to \$2,100 per year. This is equivalent to 25

minutes of support coordination service per week or 22 hours per year. No explanation was provided by the NDIA regarding the rationale behind the reduction of funding for support coordination services for Ms L following her plan review.

Case Study #10

Mr W is a 63-year-old man who was diagnosed with frontal temporal dementia (early-onset) in 2016. Mr W had lived with his wife in their family home until December 2015 when he had a seizure at home. Following the seizure, Mr W experienced a significant decline in his cognitive capacity and major behavioural changes were observed including an increase in an aggressive behaviour.

As a result of the seizure in December 2015, Mr W spent three weeks in Calvary Hospital. Following discharge from hospital, Mr W moved to a residential respite facility with a plan to transition to permanent residential aged care. In the third week at the respite facility, Mr W had a fall as a result of another seizure and was admitted to The Canberra Hospital (TCH).

The Canberra Hospital assessed that it was both unsafe and unsuitable for Mr W to return home due to his high care needs and challenging behaviours in particular. The Canberra Hospital discharge planners explored permanent residential aged care options. Two permanent residential aged care providers were consulted. Both providers advised they were unable to provide care for Mr W due to his significant behavioural issues. In absence of a residential aged care facility suitable to cater to Mr W's behavioural needs, a supported independent living service model under the NDIS was suggested and explored. Please note that at this time Mr W already held an NDIS Plan with funding for support coordination, therapy services and in-home and community based support services.

In March 2016, Community Options, the Centre for Applied Behaviour Analysis (CABA), TCH discharge planners and Mrs W (Mr W's wife) met at the hospital to discuss Mr W's to a supported independent living under the NDIS rather than an aged care facility. As a result, a plan review was requested from the NDIA. In May 2016 a review was conducted and a revised NDIS Plan had allocated funding for behavioural support and support coordination to find a suitable supported independent living service for Mr W. From June 2016, support services were provided to Mr W in the hospital setting with a view for support workers to get to know Mr W and build a relationship for a smooth transition to home (supported independent living).

By late July 2016, all preliminary work was completed by all parties for Mr W to move to a suitable property in Canberra which was accepted by the family and approved by CABA as suitable for Mr W's needs. In August 2016, NDIA advised that they would not fund Mr W's transition to the selected property. The reasons behind this decision were somewhat vague and included transition dates for other residents in the identified property still not being confirmed. Following this advice received from the NDIA, Mr W's discharge from hospital into the supported independent living service was further delayed. At this stage Mr W had lived in hospital for more than seven months.

Following this decision from the NDIA, Mrs W made a complaint to the ACT Minister for Health and contacted ABC to attract media coverage of their story. At the end of December 2016, ABC's social affairs correspondent commenced the process of writing Mr W's story. Early in January 2017, Community Options received advice from the NDIA that they would fund the supported independent

living service in Mr W's NDIS Plan. At the end of January 2017, Mr W received a new NDIS Plan with funding for supported independent living (NDIS support category: Assistance in Shared Living Arrangements – Supported Independent Living). In February 2017, Mr W was discharged from hospital into a property in Canberra. By this time, Mr W had lived in hospital for fourteen months.

5. Conclusion

Many ACT residents have had a positive experience transitioning to the NDIS. Unfortunately, as an organisation that works with people with complex needs, people with intellectual disabilities and generally those vulnerable ACT residents who often do not have a voice, we have found a number of alarming issues with the NDIS implementation in the ACT. The issues we have observed since the introduction of the NDIS in the ACT on 1 July 2015 are summarised above in this submission and the case studies tell the true stories of people who sought access or transitioned to the scheme. We trust that the information provided in this submission offers some insight into these issues. We would also like to thank you for your consideration of information provided in this submission and would like to welcome the Standing Committee's very timely inquiry into the matter of the implementation of the NDIS in the ACT. We would also like to offer our full cooperation to the Standing Committee in this inquiry. As such, we will be happy to provide further information or answer any questions the Standing Committee may have in relation to this submission.