


# Improving outcomes for marginalised rural families through a care navigator program

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## Abstract

**Issues addressed:** Health promotion programs are based on the premise that health and well-being is impacted by a person's living circumstances, not just factors within the health arena. Chronic health issues require integrated services from health and social services. Navigator positions are effective in assisting chronic disease patients to access services. This family program in a small rural town in Western New South Wales targeted marginalised families with children under five years of age with a chronic health issue. The navigator developed a cross-sectoral care plan to provide services to address family issues. The study aimed to identify navigator factors supporting improved family outcomes.

**Methods:** Participants included parent/clients (n = 4) and the cross-sectoral professional team (n = 9) involved in the program. During the interview, participants were asked about their perspective of the program. Interview transcripts were thematically analysed informed by the Chronic Care Model underpinned by Health Promotion Theory.

**Results:** The program improved client family's lives in relation to children's health and other family health and social issues. Trust in the care navigator was the most important factor for parents to join and engage with the program. The care navigator role was essential to maintaining client engagement and supporting cooperation between services to support families.

**Conclusion:** Essential care navigator skills were commitment, ability to persuade and empower parents and other professionals.

**So what?:** This descriptive study demonstrated the positive influence of the care navigator and the program on high risk families in a small isolated community. It can be adopted by other communities to improve life for families at risk.

## 1 | BACKGROUND

The Background section covers the relevance of the field of health promotion, chronic disease management and the importance of integrated care then chronic diseases in children. The section then deals with the care navigator role and introduces the study.

Under the World Health Organisation definition, Health Promotion 'enables people to increase control over their own health.

It covers a wide range of social and environmental interventions that are designed to benefit and protect individual people's health and quality of life by addressing and preventing the root causes of ill health, not just focusing on treatment and cure.<sup>1</sup> This study sits within Health Promotion sphere because it describes a program targeting people of low socio-economic background to bring about changes to improve their lives, not simply their health. The emphasis of the program is to help people gain and maintain control of their

health and their lives. People were identified as being prospective participants of the program if they had a child or children under 5 years old with a chronic health condition. Addressing chronic diseases requires complex interventions, especially in disadvantaged populations. Chronic diseases are defined as long lasting conditions with persistent effects which have a negative impact on peoples' quality of life.<sup>2</sup> Although chronic diseases are commonly associated with older people, a small but significant number of children also suffer from chronic diseases.<sup>3</sup> If the chronic condition persists it may prevent the child from leading attaining their full potential. However, with appropriate management, many children with chronic conditions can function well and live almost normal lives. How the chronic health issue is resolved in young children is influenced by how the family copes with the stress, time, energy and personal resources expended.<sup>3-6</sup> There is convincing evidence that low socio-economic status has a negative impact on a range of children's health issues.<sup>7</sup> Children from low income families are more likely to exhibit psychological or social difficulties, behavioural problems, lower self-regulation and higher physiological stress markers.<sup>8</sup> Australian figures from 2016 show that 22% of children were living in households with housing stress which can lead to physical and psychological health issues.<sup>9</sup> In addition, children of Indigenous backgrounds are more likely to report health issues.<sup>10</sup>

In rural and remote communities, social disadvantage is compounded by lack of access to services.<sup>11</sup> Residents of isolated rural communities in Australia experience poorer health outcomes than their urban counterparts. This is due to a range of factors including: reduced local resources; poorer access to services; lower availability of health professionals; higher Aboriginality; lower socio-economic status and greater distances to travel for services.<sup>12-15</sup>

Chronic disease management requires access to a range of different services, including general medical, allied health and social services. The integration of these services presents a major difficulty for patients, carers and families because of poor communication between different sections of the health sector and between health and social services.<sup>2</sup> For families living with stress due to low income and poor housing and single parent families, accessing the range of services needed for a chronic condition often presents an insurmountable burden.

Integrated Care is 'the provision of seamless, effective and efficient care that reflects the whole of a person's health needs; from prevention through to end of life, across both physical and mental health, and in partnership with the individual, their carers and family. It requires greater focus on a person's needs, better communication and connectivity between health care providers in primary care, community and hospital settings, and better access to community-based services close to home.'<sup>16</sup> As part of a major integrated care policy initiative of the New South Wales (NSW) Ministry of Health,<sup>16-18</sup> the Western NSW Local Health District (WNSW LHD) received funding from the NSW Ministry of Health to implement integrated care programs in Western NSW. The target group in this study was children in the first 2000 days of life with chronic and complex care needs. The model of integration involved establishing

a new funded care navigator position to recruit and enrol patients/clients in the target group and arrange for the coordinated implementation of a care plan through case conferencing with relevant health and social care services.

The WHO states that 'enabling young children to achieve their full developmental potential is a human right and an essential requisite for sustainable development. Given the critical importance of enabling children to make the best start in life, the health sector, among other sectors, has an important role and responsibility to support nurturing care for early childhood development.'<sup>19</sup> It is the responsibility of the family to provide nurturing care to their child(ren) to support early development. As not all parents/caregivers are able to provide the level of nurturing care required, a range of early childhood development services have been available to assist. The WHO propounds that a nurturing approach should be the central tenet of achieving optimal care.

Chronic diseases of childhood, if not resolved can have a profound effect on quality of life and life expectancy. The impact is more pronounced in vulnerable single parent families with underlying stresses of poor housing, low income and inability to access services. Children with a chronic disease may miss school, thereby failing to gain an education which disadvantages them all through life. Bell et al<sup>20</sup> reported that childhood chronic disease in Australian children of preschool age had an impact across the domains of physical wellbeing, social competence, emotional security, and communication skills and general knowledge and language and cognitive skills. A health promotion approach to chronic diseases of childhood embraces not just the immediate medical aspects of the disease but also the social and environmental aspects. Adopting a narrow medical approach may exclude the essential assistance for vulnerable parents to cope with and manage their child's condition.

This study focuses on the role of the care navigator in working with families with young children with a chronic condition. Navigator positions can assist the growing number of people with complex and chronic conditions especially those who are underserved or disengaged with the system.<sup>21</sup> Navigator positions, usually occupied by skilled nurses, acting as 'brokers', are relatively new in primary care but have been used extensively in coordinating services for people with cancer.<sup>22,23</sup> Their role fits within the health promotion arena by engaging with participants/patients to improve access to components of the health system and other social services, thereby coordinating care and facilitating patient centredness.<sup>23</sup> In keeping with health promotion principles, the navigator engages the participant to take control of their own lives. In this program, the care navigator was occupied by an experienced nurse with well-developed local knowledge of the community and its services. The position criteria have been changed from a nurse-only role to include suitable people with social services experience to acknowledge the importance of the involvement of health and social services.<sup>24,25</sup> A program of 'Nurse Navigators', senior advanced practice nurses for patients with complex chronic conditions was introduced in Queensland, Australia in 2016.<sup>26</sup> The relationship with the patient developed by Nurse Navigators was reported to increase the supporting mechanisms

of valuing, improving health literacy and patient coping skills.<sup>27</sup> The navigator position should be developed in consultation with other providers involved in care.<sup>28</sup> Improved patient outcomes resulting from care navigator intervention have been reported<sup>22,23,29</sup> and in vulnerable and underserved populations.<sup>30</sup> Descriptive studies in the UK<sup>31</sup> and Australia<sup>32</sup> in general practice showed a high level of patient satisfaction with navigator positions and that GPs were able to delegate work to the navigator thereby freeing up their time. Also important was the facility to undertake 'social prescribing' for patients to ensure access to the full range of health and social services.<sup>31</sup> A review of the care navigator literature revealed that most studies were descriptive demonstrating the need for controlled studies.<sup>22</sup> Further studies on the navigation role are needed to determine impact and cost-effectiveness and explore the perception of patients and families.<sup>23</sup> In this report the term 'care navigator' has been used because that is the designation in the program under study.

The care navigator role can be seen in the broader context of the Chronic Care Model<sup>33,34</sup> which specifies that proactive professionals work to activate patients/clients to improve the management of their chronic condition. The care navigator provides the focus for activating clients to address the issues of concern. We have adopted the Chronic Care Model as the theory underpinning this study.

This paper reports a cross-sectional descriptive case study of a health promotion based integrated care program in a small isolated community in Western NSW, targeted at families with a child or children under 5 years of age, with a chronic health condition. The chronic health issue could be described as the 'hook' for pulling families into the program. Once families have been recruited into the program, the health and psychosocial problems are identified and addressed using a team of health and social services workers which is spearheaded by the care navigator. The program fits within the nurturing care framework detailed in the WHO Improving Early Childhood Development Guideline.<sup>19</sup> The aim was to describe the care navigator role, the problems addressed by the care navigator and the key factors which contributed to favourable client outcomes. We wanted to develop a picture of what success in a care navigator program in a disadvantaged community looked like.

## 2 | METHODS

Researchers (KE and SK) visited the health service site to observe the program in context and collect data by semi-structured interviews and observation of case conferences and leadership group meetings. The clinicians, social care and education provider participants and four parent clients were recruited by the local care navigator. Face-to-face interviews on site at the health service or telephone interviews were arranged to fit with participant competing demands. Ethics approval was provided by the Greater Western Area Health Service Human Research Ethics Committee (HREC/17/GWAHS/5) and by the Aboriginal Health and Medical Research Council Human Research Ethics Committee (1269/17).

The interview questions focused on the participant's experience of the program. Professional participants were asked about the way in which the team worked together, the role of the care navigator and their perception of the implementation and sustainability of the program. Parent clients were asked to recount their experience of the program and how it had impacted on their family life. Interviews were recorded for later transcription, by a transcription service, and checking and analysis using Nvivo software (QSR International <https://www.qsrinternational.com/>). The case conferences and Leadership Group meetings were not recorded but notes made after the meetings to supplement the interview data.

### 2.1 | Setting

The population of this small isolated community in Western NSW is just over 2000 people of whom around 29% are of Aboriginal or Torres Strait background, compared to 3% average for the State of NSW.<sup>35</sup> Health services consist of a local hospital and community health service and an Aboriginal Medical Service which provide a range of generalist health and medical services. Specialist services are more difficult to access, residents can wait for an appointment with a visiting medical specialist and allied health services in the town or travel to a larger centre which is 3 hours by car. Waiting times for visiting services are up to nine months or more for some specialities. Unemployment in the town is 10.6% compared to 6.3% for the State of New South Wales. The rental housing stock is low and poorly maintained. Community consultation was initiated as a prelude to the program and involved other health and social care services and community members. The consultation, organised by the local health service, resulted in the town nominating to participate in the Integrated Care program with the identified priority target group of children in the first 2000 days of life with a chronic health condition. The most common condition in this local town is chronic ear infection. Families invited to join the program were identified by the care navigator through consultation between service providers, including the health service, the Aboriginal Medical Service, social care services operated by the government and non-government sectors and the local schools. Families were approached by the care navigator and asked if they were willing to participate in the program and share their personal health and other data being used across services. Client issues were identified and prioritised in discussion between the care navigator and the client family and a care plan developed. In this program, the care navigator position was specified as a nursing position.

A case conference was convened by the care navigator fortnightly involving health and social services and the schools to discuss care and services and organise referrals within and outside the town. The care navigator role included identifying and recruiting the service providers to the case conference. The children under 5 were the primary clients of the service, but the whole family was involved in the care plan. A Leadership Group with representatives from the services involved was held fortnightly

to oversee the program and provide governance. Client program records showed that 20 families were enrolled at the time of the interviews in August 2018, involving 78 clients of whom 69 (89%) were Aboriginal. Thirty-one of the client group were 5 years or under, while a further 20 were aged between 6 and 18. Of the parents (aged 18–58), the average age of females was 29.0 ( $n = 16$ ), while that of males was 39.9 ( $n = 7$ ). Client enrolment ranged from January 2017 to April 2018.

## 2.2 | Aim and research question

The aim of this cross-sectional study was to describe problems addressed by the program, to identify key factors in the care navigator role which supported favourable client outcomes and the kind of outcomes reported. The research questions were: (a) how does the role of the care navigator contribute to positive client outcomes? (b) what does success in this program look like?

## 2.3 | Methodological orientation and theory

We hypothesised that this program was dependent on the care navigator role for providing the skills of leadership and motivation for integration of care. The theory underpinning the study was the Chronic Care Model which draws on health promotion principles. This phenomenological study examined the phenomenon of the relationship between the care navigator, the client families/parents and the participating professionals through interviews and observation.

## 2.4 | Participant sample

A purposive sample of parent client and professional participants was identified by the care navigator. Local participants included: four parents of clients, six health or social care and three education professionals. Two of the parents were Aboriginal. Other parent participant details have not been reported to protect their confidentiality. Interviews were conducted by SK and KE face-to-face on site in the health facility or by phone. Interviews were recorded and transcribed by a transcription service. The care navigator adopted a sensitive approach in identifying program parent clients for interview by inviting those whom she perceived would find the interview neither stressful nor intrusive. The number of participants was small. Participants were identified by the care navigator as those parents who might agree to be interviewed. The research team left this judgement up to the care navigator as parents on the program were considered vulnerable. Any direct approach from people not known to and trusted by participants was considered unsafe. As well as local employees of the WNSW LHD, three senior managers with responsibility for the program were also interviewed as shown in Table 1.

## 2.5 | Analysis

Transcripts were analysed as they were collected<sup>36</sup> by SK and KE using NVivo software (<https://www.qsrinternational.com/>). This was guided by the research question, using the framework of the Chronic Disease Model.<sup>33,34</sup> The Chronic Disease Model stipulates that care provided (a) by a skilled proactive team to (b) informed and activated patients (c) through productive interactions between the two resulting in (c) effective self-management and (d) improved outcomes. In the participant interviews, the researchers highlighted the care and services provided as part of the program, level of engagement between professionals and clients, the ability of clients to self-manage and the changes in the client's life/outcomes of the program. Emerging themes were discussed by SK and KE to reflect on the meaning of the data in relation to the research aim and question. Thematic analysis was undertaken by identifying themes which emerged from the interview data and linking them to the Chronic Care Model. The analysis explained the relationship between the care navigator, the client families/parents and the participating professionals. The findings were discussed with and checked by the care navigator for accuracy. Findings were checked and validated by the research team of co-authors during the preparation of the paper.

As far as possible with the small sample and the need to preserve the confidentiality of the parents, the consolidated criteria for reporting qualitative studies<sup>37</sup> was used to guide the framework for this report.

## 3 | FINDINGS

### 3.1 | Clients/parents interview data

The broad themes extracted from the client data can be grouped around: family life, including housing/overcrowding; access to services and client and service provider attitudes.

The Chronic Disease Model provided a framework for examining the findings by focusing on the gradual activation of clients by the engagement of a team of professionals which became more proactive, guided by the care navigator.

#### 3.1.1 | Family life

The client/parent findings included the broad themes of family life, services provided and the skills and attitudes of the care navigator and other service providers. The four clients were single parents in their twenties with five children each. The care navigator indicated that they were not atypical of the whole parent program clients. Their major difficulty was in managing their children and family life in sub-standard overcrowded rental accommodation. Parents reported that they would not have joined the program without the gentle persistence of the care navigator, a local woman well known and trusted in the community. For these four families, the first step in the care

**TABLE 1** Participants

Clients						
Parent client	Gender	Age range years		Number of children		Aboriginality
1	Male	20-30		5		No
2	Male	20-30		5		No
3	Female	20-30		5		Yes
4	Female	20-30		5		Yes
Professionals						
Type of professional/role	Organisation	Gender	Case Conference attendee	Leadership Group attendee		Permanently funded position
Care navigator – case conference convenor, coordinator of parent/child care plan	WNSW Local Health District Community Health	Female	Yes	Yes		No
Manager – facilitate involvement of Family and Community Services case workers	Family and Community Services	Female	Yes	Yes		Yes
Wellbeing Officer – liaison with school and parents	High School	Female	Yes	Yes		Yes
Manager – coordination of Aboriginal Medical Service case workers	Aboriginal Medical Service	Female	Yes	Yes		Yes
Senior Program manager – executive oversight of program	Kids and Families Program WNSW Local Health District	Female	Yes	Yes		Yes
Manager – involvement of case workers	Mission Australia	Female	Yes	Yes		Yes
Child and family Health Nurse – direct care for parents and children	WNSW Local Health District Community Health	Female	Yes	Yes		Yes
Health Service Manager – support and facilitation of health workers	WNSW Local Health District Community Health	Female	No	No		Yes
Team Leader – support and facilitation of health workers	WNSW Local Health District Community Health	Female	No	No		Yes
Senior Manager – executive support	WNSW Local Health District Health Intelligence Unit	Female	No	No		Yes
Senior Manager – executive support	WNSW Local Health District Integrated Care Program Manager	Female	No	No		Yes

provided was for the care navigator to negotiate better housing. Once housing was improved, family life became more manageable and the focus of care shifted from housing to arranging health and social care appointments and transporting clients and children to services. Most of the chronic children's health issues were resolved in part or fully with appropriate care. The most common health issue was chronic ear infection. In older siblings who were attending school, speech and language issues and behavioural issues were identified.

### 3.1.2 | Access to services

Services were arranged for family members to address issues. Usually there was a wait for services from visiting specialist services, such as ear nose and throat medical specialist, speech pathology and occupational therapy. The wait was frustrating for parents who needed the care navigator's encouragement and support to get through this time. Families also required on-going help from the care navigator to manage accessing social care services. One of the

school representatives interviewed reported that absenteeism in older siblings was reduced in families on the program.

Family lives had been chaotic prior to the program. A multiplicity of issues with former partners and difficulty getting their children organised meant that they had little time for addressing their children's health.

"I've had a pretty hectic life. And everything sort of just fell to bits between me and the kid's mum there."

Parent 1.

### 3.1.3 | Client and service attitudes

They described their initial reluctance to join the program because their experience in the past with health and social services had been negative.

"And a whole heap of stuff got blown up and I told [care navigator name] I didn't want any of her help.

And I didn't need any of her help and told her, "Leave me alone." Then we ended up sitting down and talking about it and I apologised 'cause I come off a bit hot-headed. Ever since then it's been great. At first, I was just, like, "Go away. I don't need you. I don't need anyone intervening in me and my kid's lives." And I'm glad it come back around the other way." **Parent 1.**

Parents indicated that if they missed appointments with doctors and other health professionals because of other priorities in their complicated lives, they felt that they were being judged as being unreliable by service providers. They had been reluctant to return to make other appointments for fear of being discriminated against. The care navigator was able to help by ringing to remind them of appointments, arranging transport and encouraging them.

"[Care navigator name] helps me with my paperwork. She helps me with all my appointments. She goes out of her way to help me." **Parent 1.**

"Through the kids, and helped get to the dentist, well, make an appointment because I was working, working part-time at the time, I still am now, and raising five kids on me own then, so I was pretty, it was pretty hard. So, she's [care navigator] helped me if I need something, I say, "I can't get there, I'm at work, it's too hard." So, I'd ring up and see if she can organise something, like the dentist." **Parent 2.**

"[Care navigator name] ended up being really, really helpful from that sense. One of my girls has to go away to Dubbo to get her ear done..... we thought she was on the waiting list and the paperwork hadn't been sent so [care navigator name] followed that up for me. She's now on the waiting list." **Parent 3.**

One parent described how the Department of Community Services had assumed that he was using illegal drugs when he did not answer telephone calls from them and arranged drug tests. With the help of the care navigator this issue was resolved.

Poor rental accommodation was a problem experienced by all four clients. One parent said that the Department of Housing regarded her as a 'pest' because she tried to get a bigger rental house. She felt fobbed off. Housing issues for three of the four parents had been resolved and the fourth was on the waiting list for housing in a larger town where specialised services had been arranged by the care navigator not available in this town.

"I was living in a home and they sold the home from under me, pretty more or less, me and my children and I was pregnant with my baby. And so we had to move in with my mum and dad and then that got a

bit too much so I come to [care navigator] and said that I couldn't stay there anymore and she helped me get in - well, we were staying in a motel for a bit and then we got into the refuge but now we're in our own home." **Parent 4.**

Two of the parents indicated that older children in their families had behavioural issues which disrupted the whole family.

"He's been like it ever since he was born, so there's a chemical imbalance going on. We made paediatrician appointments and they were 18 months waiting list. And then everything went pear shaped and we got the letter in the mail and we weren't there. And you come back and collect the mail - - - Him and his little brother fight like cats and dogs. 'Cause [second child name] is OCD And that's what [care navigator name] printed me out ways to deal with him." **Parent 1.**

"[Care navigator communication] Yeah. Down on your level too. That's what the appointment's like. I said, five kids, and I get overwhelmed." **Parent 1.**

"[Talking about care navigator] Very persistent though. She always follows through with what she says she's going to do, and she always comes to check on us to make sure that we're right or if we need any help with anything else." **Parent 4.**

"I think it's the consistence from her [care navigator]." **Parent 3.**

"And, yeah, not giving up [care navigator] and just being friends and...

Even us making sure we're looking after ourselves." **Parent 4.**

"And if something does big come and I know I can call her, and I know even if it's just talking support, I'll have someone to talk to. If it's just paperwork. In lots of different areas, I would be lost. My kids wouldn't be getting the dental work done they're getting. And I wouldn't be getting appointments done that I'm getting. 'Cause I wouldn't mean not to but I'd just be forgetting about them. Not making them. Even making appointments so they're four months down the track and for remembering." **Parent 1.**

The four parents were being supported on the program to undertake part time employment. They were proud of what they had achieved.



### 3.2 | Professionals data

Observations of the case conference and the Leadership Group meetings provided a first-hand demonstration that the local professionals had developed strong working relationships of trust enhanced by their detailed knowledge of the roles of each of the services in the program. They worked cooperatively to facilitate referrals across services and improve the lives of families, exhibiting a nonjudgemental approach to the families. They were compassionate and highly motivated to improve family outcomes. Although some clients were not willing to engage with the program and accept services and care, efforts were still made to encourage the families to join the program.

The researchers (SK and KE) saw evidence of the well-developed liaison skills in, knowledge of services and knowledge of families demonstrated by the care navigator which she used to plan and guide the care delivered.

### 3.3 | Professional interview data

The families on the program were known to the individual professionals in the case conference group. However, each professional working in isolation from other services was not able to resolve family issues. It was only after joining the program group that they began to see progress. Professionals indicated that the level of cooperation was due to the efforts of the care navigator, who described her work with other services in the following way:

"So, you have to be a bit like a hound dog and keep going back and back and back. And you have to work on building these relationships." **Care navigator**

Professionals identified good working relationships with a high level of trust as important in implementing the program. However, high turnover of staff in the town, particularly at case manager level, was a barrier to implementing the program. Staff shortages, exacerbated by the high turnover, were also identified as a barrier to care across all services.

"The unfortunate thing with the other services is, you just get a great working rapport with a staff member, and they leave .... Because [town name] is a very hard place to work. Particularly if you're not from the area .... Look, usually the managers in these other things are pretty stable. So, it's the caseworkers. Because they're on overload. So, they tend to burnout and go or leave for a majority of reasons." **Care navigator.**

Professionals noted that different services often shared clients/families: not surprising as the same families would be accessing services from health, FACS (including the Department of Community Services, DOCS) and the Non-Government Organisation Mission

(which provided a family program, the Brighter Futures Program<sup>38</sup>) and the schools. Thus client/family information was able to be shared to facilitate planning and providing the appropriate suite of services. It was observed that families who were assessed by Family and Community Services (FACS) as relatively low risk and therefore not eligible for FACS services were picked up by health for identified chronic health issues, thereby preventing possible parental neglect of children and more serious interventions in the future.

"We've got one example in town who is a mum with five young children and she's only 22. And in fact, yes, hard work, and neglect has been an ongoing issue at different points, and we would be picking it back up again as quite high risk, except for [care navigator] is trying to engage with Mission [NGO Brighter Futures Program] at the moment, so integrated care. If they do, it will actually prevent us being re-involved in a statutory matter in her life..... Yes, and more appropriate in lots of sense in that it doesn't carry the same stigma and shame with it and, really, it's not a mum who is abusive in the sense, it's about knowledge, skill, access." **FACS Manager.**

Cooperation between the Aboriginal Medical Service (AMS) and health was evidenced by the care navigator being collocated with the AMS for part of the week. In addition, the fact that she was able to access the medical records of program clients at the AMS facilitated the development of the care plan and appropriate referrals.

Case conferencing was a vehicle for sharing important information about families. For example, the school representative indicated that she was able to provide information on older sibling's attendance, truancy and suspensions at the case conferences which added to the picture of family life and informed better care planning. Professionals indicated that this sharing of information was a result of the care navigator's skills in building cooperation in the multidisciplinary cross-sectoral team.

Although they had demanding workloads, professionals represented in the case conferences and leadership group emphasised the high priority they placed on attendance at meetings because it was important for families in need and at risk.

"So, we're absolutely under the pump, they are still supportive of me attending these because it does benefit our clients and our kids ... " **FACS Manager.**

Housing services were identified as a big issue for families with many children. The overcrowded accommodation led to behavioural problems reported by the schools and preschools.

*"Not the youngest, but the two above the youngest had referrals to the child psychologist because their behaviour was so violent, so out of control, it was just dreadful. So, we started the ball rolling, working. But anyway, through*

*a lot of work and support networks and push and we managed to get [parent] a bigger house. Now within two weeks it was evident that those kids didn't even need to see a psychologist anymore." Care Navigator.*

Professionals indicated that because working across sectors through inter-agency meetings was embedded in their role descriptions, their participation in the program was assured in the future.

At the most senior level, the support for the program was driven by the Chief Executive of the WNSW LHD through the monthly meeting of the heads of services across the area, including the AMS. The local Health Service Manager indicated that she was able to identify issues for discussion at the meeting in relation to the program. In spite of this, the sustainability of the program is at risk because of temporary funding of the care navigator position.

Professionals expressed the view that the 'on again off again', short term project funding, rather than permanent funding for programs, had engendered a feeling of mistrust in the community.

*"Another thing that I find makes it very difficult is the fact that the government bring in these services, they put this money into something and open it up and they bring it in and it takes you ages to build trust with the people, and they withdraw the funding and take it away. And then they bring in another program and it has to start all over again." Health Service Manager.*

Important service gaps identified by professionals included paediatric services, for which there is a 10-month waiting list. Visiting services from dental, speech pathologists, occupational therapists and ear nose and throat specialists are provided but also involve a long wait of some months. Another problem with services in short supply was that parents gave up. Health service employees were lobbying for an increase in visiting specialised services in the town.

*"No, so even if we could get them in, and I think a lot of hope gets lost by people knowing that stuff is not available, so they don't bother. But our oral hygiene stuff is a huge one, I think that probably impacts a lot on other stuff, particularly with speech. I have never seen the amount of oral decay here and I know it sounds like I'm harping on it, but watching kids walk around the street with black teeth, or with meat pies and soft drinks." FACS Manager.*

The skills identified and demonstrated by the care navigator to establish and maintain the program included tenacity, compassion, commitment, a nonjudgemental approach and liaison skills. Also necessary was the ability to engender community trust, knowledge of the town and a profile in the town. Other service professionals needed to be nonjudgemental, committed to participating in the multidisciplinary cross-sectoral team process of care planning and delivery.

Under the existing resource allocation, the program is unable to recruit new clients because of the heavy workload on the care navigator position. It is envisaged that parent clients will become more independent over time as they gain skills and confidence and will require less time with the care navigator and could eventually be discharged from the program or be allocated to a maintenance program with a lower level of servicing.

## 4 | DISCUSSION

The study was designed to elucidate the role of the care navigator and describe the elements of success. In essence, the care navigator role is based on health promotion principles because the emphasis is on the clients taking control. The scope of the role is broader than simply addressing health issues. The role of the care navigator position also includes providing leadership for the team of health and community service professionals in the program by identifying and recruiting clients with children under five years with a chronic health condition and arranging the appropriate services to meet their needs. Using a health promotion approach, the care navigator undertook a process of engaging clients to participate in the program which required considerable powers of persuasion, patience and compassion. This nurturing aspect of the care navigator aligns with the WHO Guideline on Improving Early Childhood Development.<sup>19</sup> The process of engagement was lengthy and included the following changes in the parents: initial reluctance and sometimes hostility; growing trust in the care navigator; strong relationship with the care navigator; realisation of potential outcomes and achievement of positive outcomes. The success of the program hinged on the elements of patient activation which align with the process detailed in the Chronic Care Model<sup>33,34</sup> in which there is a two-way relationship between proactive professionals working with activated patients with supporting systems. It is also a feature of adult chronic disease patients and clients of chronic disease management programs in urban<sup>39</sup> and rural<sup>25,40</sup> settings. The care navigator role is the lynchpin in the process of successfully activating clients and engaging proactive professionals. The elements of the care navigator role in building and sustaining relationships with clients and the team of professionals underpins the achievement of positive family outcomes.

The multidisciplinary cross-sectoral team of service providers had a high level of trust with each other, commitment to cooperate to achieve client outcomes, a comprehensive understanding of the services available and a nonjudgemental approach, especially as some of these families were experiencing drug, alcohol and child neglect issues. In keeping with health promotion principles, all aspects of the client's life were addressed, not simply health issues. The care navigator provided leadership here: her nonjudgemental attitude helped engage client parents and provided an example to other members of the team.

The involvement of the professionals was supported by their organisations. They were given time to take part in case conferences and leadership group meetings and working across sectors was enshrined in their job descriptions. This enabled them to commit to



developing and implementing agreed care plans, with timely referrals to required services and on-going support for families.

The care navigator position was originally specified as a nursing role. The requirements have been broadened to specify qualifications and/or experience in health care settings, social welfare, health/social program management or community partnership development to ensure a wide range of skills in nursing and other health and community settings.<sup>25</sup>

Problems identified by the parents included social factors, in particular, overcrowded housing. As well as being a health risk in its own right (10), housing needed to be addressed before parents were able to focus on more direct health issues. Once housing was improved life became easier and the focus of the care navigator shifted to other health and social problems which were identified during the case conferences. The range of issues that client parents experienced was extensive, requiring the resolution of complicated bureaucratic processes. The client parents were lacking in confidence and felt discriminated against, and so needed support from the care navigator to go through the necessary procedural hurdles to access services and resolve issues. With the help of the care navigator, they learnt new skills in dealing with their issues and their confidence grew. They trusted the care navigator to help them and they relied on her for on-going support.

The parent descriptions of their lives after joining the program demonstrated that they had grown in confidence of their ability to manage as parents with the help and support of the care navigator. They were proud of their achievements in turning their lives around. The fact that the four parents interviewed were in part time employment was testament to their new-found ability to better manage their lives. The relationship with the care navigator was a transformational experience involving the acquisition of new skills in dealing with bureaucracy and parenting skills. Previous poor parenting skills could be explained by chaotic lives and a lack of positive parental role models.

This family program is an example of a health promotion/primary health care approach in which health is perceived as more than the absence of illness and includes a cross-sectoral approach to social and other factors.<sup>41</sup> This approach is necessary to make headway with complex problems which beset families who are poor and less resourceful. However, it is also resource intensive.

#### 4.1 | Strengths and limitations

This study reports close observation of a complex intervention in a small, highly disadvantaged rural population. The sample of clients and professionals is necessarily also small but allows for an in-depth description of the kind of problems that such a program needs to address. The identification of the elements of success in this small-scale study should be helpful in guiding the establishment of similar programs.<sup>40</sup>

Recruitment was through the care coordinator: this was felt to be the only viable option in such a marginalised community. This may have biased the sample of clients, but it is likely that their experience

is not atypical. The measurement of client/family health and social outcomes would have complemented the qualitative findings.

This study, by providing a detailed description of the skills and role of the care navigator, contributes to the growing body of research on health navigator positions. The success of the program was evident for the small sample of parent clients. The study will be of interest to those wishing to replicate a similar integrated program. It demonstrates that care navigation can improve family outcomes in rural locations.

## 5 | CONCLUSION

The care navigator, working within a supportive program, was able to help parents with chaotic lives and complex conditions to use and benefit from services. This study demonstrated that children's health and other health and nonhealth problems improved when they joined the integrated care program and that clients' parenting skills and confidence in dealing with bureaucracy increased. Key factors supporting the program were the commitment of professionals involved in working across sectors and to being nonjudgemental. The care navigator skills included tenacity, well developed liaison and persuasive powers to engage both clients and other service providers and to maintain the on-going relationships.

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## SUPPORTING INFORMATION

Additional Supporting Information may be found online in the Supporting Information section.

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