

Families with complex health and social needs

Contents

Families with complex health and social needs.....	1
Introduction	2
Overview	3
Complex health and social care needs and Aboriginal and Torres Strait Islander families.....	5
Complex needs in culturally and linguistically diverse (CALD) families	5
Support for families with complex needs	5
Key Issues.....	8
Integration of health and social services	8
Communication between providers	8
Support Coordination	8
Respite	9
Priority Issues.....	10
Need for better coordination of services for families with complex health and social care needs	10
Identification of families with complex needs.....	11
GP advocacy for families with complex needs.....	12
References	12

Introduction

'Complex needs' is defined by the National Complex Needs Alliance as a combination of health needs (e.g. diagnosis, treatment and rehabilitation) and social needs (e.g. housing, social care and independent living) (National Complex Needs Alliance, 2014). In a family with complex needs there may be family members with a range of differing health needs, for example, with disability, mental health issues, drug and alcohol problems, chronic conditions or be victims of abuse, all trying to navigate their respective support needs and assisting in caring for other family members. They may also be experiencing financial issues, having trouble accessing education and training, getting work, homeless or at risk of homelessness, and may have come in contact with the legal or criminal justice system. They may therefore be in contact with a range of support services including, schools, health care (GPs, community health centres), non-Government and Government services (National Disability Insurance Scheme), or they may be receiving minimal support and/or falling through the cracks of service delivery. As well as the huge social and human costs, the economic costs to the government are significant.

In an attempt to illustrate what we mean by a family with complex health and social needs, we provide the following vignette/case study as an example of the issues:

The case involves a family with multiple morbidities who have been unable to access a sufficient quantity of regular respite care in the ACT for a young person in their care, resulting in family breakdown.

- *The family have a child who is 13 years old with an intellectual disability and behavioural issues.*
- *One parent has a chronic illness and is permanently incapacitated, the other parent has undiagnosed issues with substance misuse and different cultural perspectives of parental responsibility and disability and there are two younger siblings.*
- *The child's condition has led to violent behaviours towards other children at home and in the community resulting in the police being called on a number of occasions.*
- *Adequate respite care is not available to the family with the closure of all secure facilities for children in the ACT.*
- *A number of agencies are involved with the family including the Community Services Directorate (CSD), ACT Health, the GP, the NDIS, two not-for-profit family support services and police.*
- *Information is not being shared resulting in a lack of coordination between agencies and large scale resources not provided.*
- *This is a complex family situation where there is the potential for serious harm. A comprehensive approach to early intervention, therapeutic care for the children, parent counselling and adequate respite could resolve some of the issues rather than an Emergency Department or criminal justice presentation for one or more members of the family.*

This case study highlights:

- *the approach of the NDIS in focusing packages on individual need and not including the broader situation of the family/carers*
- *the lack of connectivity between services in the ACT including health, CSD, policing and family support services*
- *the lack of lead case managers or care coordination for complex family situations*
- *the lack of funding for case conferencing and resourcing for intensive family support*
- *the lack of options for adequate levels of respite*
- *variability in referral systems that lead to a lack of flexibility in urgent and complex cases.*

Overview

Families with multiple and complex needs may be experiencing numerous, chronic and interrelated problems. Although there is no single definition, there is widespread agreement that families with multiple diagnoses and complex needs include those experiencing addiction, disabilities, mental or chronic physical health needs as well as those living with poverty and/or a combination of these things (Social Policy Evaluation and Research Unit, 2015). These can result in both a breadth and a depth of need (Bromfield et al., 2012). In most cases, there are entrenched unmet needs that no single agency can meet alone. Families with complex needs often have significant unmet survival needs, related to food, housing and personal safety. Evidence suggests it is only when these survival needs are met that providers can begin to work with families on other issues as part of addressing their complex needs and support services can be effective (Social Policy Evaluation and Research Unit, 2015).

Families with complex needs are often situated within a context of social exclusion and entrenched disadvantage and many of these families find services 'hard to access', while the services view these families as 'hard to reach' (Social Policy Evaluation and Research Unit, 2015).

One of the main challenges for parents experiencing multiple and complex health and social needs are the capacity to care for their children and parent effectively (Bromfield et al., 2012). Parents are likely to be preoccupied by attempts to deal with and manage pressures, so they are not able to give parenting the attention needed and their parenting capacity may become depleted or compromised. Their parenting may include disengaged, unresponsive, inappropriate, harsh, punitive or abusive responses to children.

Relationships with partners may be under extreme pressure and subsequently become conflict-ridden and unstable, and both couples and single parents may lack sufficient family and social supports. Family members may be experiencing the same stressors but to complicate things, they

present with different reactions, behaviours and problems linked to those stressors and linked to each other's behaviour and problems (Bromfield et al., 2012). For example, a child's stealing, a father's absence and a mother's depression may all be related to financial hardship.

Over time, the stress, compounding difficulties and cumulative impacts mean that a family can struggle to function, experiencing episodic crises, escalation of individual and family relationship problems, role breakdown or family fragmentation. As family members become increasingly overwhelmed, the effect on individual functioning and on family dynamics can exacerbate contexts in which mental illness, family violence, substance abuse and child abuse occur or escalate (Bromfield et al., 2012). It can also increase the wider risks to the community.

Families with multiple and complex needs are typically situated within a broader context of social, economic and structural disadvantage. Poverty and the interlinked problems of poor health and housing, poor educational and employment opportunities and skills, lack of social capital and family and community supports, crime, mental health difficulties, substance use and violence, early childhood trauma and poor parenting experiences all contribute to social exclusion (Bromfield et al., 2012).

Increasingly, families with multiple and complex needs have become the primary client group of child protection services. Research has shown that they typically have five or more disadvantages including living with poverty, unemployment, poor quality housing and disabilities. Experiencing serious, multiple disadvantage cuts across many domains of family life. Families with multiple and complex needs are likely to have difficulties meeting the needs of their children and parenting effectively. Children can be at heightened risk of abuse and neglect and at higher risk of adverse outcomes (Bromfield et al., 2012).

Ultimately such families will be able to make and sustain changes and better meet the needs of their children if service responses, including child protection, address the needs of whole families and where possible assist with the broader systemic factors in which their difficulties are created and situated.

Children and young people with complex needs often have a range of interrelated problems such as intellectual disabilities, mental health issues, educational difficulties and histories of school suspension/expulsion.

Complex health and social care needs and Aboriginal and Torres Strait Islander families

Aboriginal and Torres Strait Islander families are over-represented in populations of families with complex needs (Social Policy Evaluation and Research Unit, 2015). Many Aboriginal and Torres Strait Islander children and families are vulnerable to experiencing multiple and complex needs and this can lead to social, community, family and individual difficulties (Australian Institute of Family Studies, 2016). Practitioners need to understand the profound impact of past and present experiences on Aboriginal and Torres Strait Islander people and have a knowledge and understanding of key aspects of their cultures, values and beliefs. Practitioners also need to be open and respectful when addressing problems and concerns with Aboriginal and Torres Strait Islander families. Culturally aware and respectful practice needs to be embedded throughout all services for Aboriginal and Torres Strait Islander families.

Complex needs in culturally and linguistically diverse (CALD) families

Families from culturally and linguistically diverse (CALD) and refugee backgrounds may be more vulnerable to experiencing multiple and complex health and social care problems. These families may experience isolation, communication difficulties, racist attitudes, family violence and substance abuse (Parker, 2009). Experiences of resettlement in Australia can vary immensely, depending on a person's support networks, mental health and wellbeing and English proficiency.

Support for families with complex needs

Families with complex needs require long-term, individualised and intensive support (Katz et al., 2006). These families generally use more health services and receive care from more and different health professionals than other families. These families may also have functional limitations, which means they often need assistance from family members or paid carers to perform activities of daily living. As a result, they are more vulnerable to fragmented care and 'falling through the cracks', often 'lost to the system' until a crisis occurs.

Research has found that to be effective, approaches need to be: collaborative, multi-faceted; multi-systemic; well-structured; family-centred; strengths and capability-based; and culturally responsive (Social Policy Evaluation and Research Unit, 2015). Effective approaches develop partnerships with families and/or communities, use trained facilitators who create trust, and are well coordinated and sustainable over time.

A project was completed by the ACT Government along with community services and families accessing the ACT service system in 2012, examining the journey families undertake within the ACT

service system, and what can 'be done to better enable all families in our community to live their lives successfully and with dignity' (ACT Government, 2012). The report found the families experienced many issues when dealing with the human service system, which included feeling misunderstood and not being taken seriously, having to repeat their story multiple times, having their case closed by a service provider without their knowledge and resolution of issues, and not being provided the assistance they were told they would receive, including prolonged involvement with services and the absence of any positive progress (ACT Government, 2012). Many of the outcomes of these experiences left the individual or family feeling disengaged and having feelings of mistrust with the system and its ability to help them. Families also felt that individual-orientated, single-problem-focused services meant that only one family member or problem was addressed. It was also evident that the system was working in a reactive manner and families weren't eligible for assistance until they reached crisis point (ACT Government, 2012).

Human Services Blueprint

The Human Services Blueprint is a whole-of-community and whole-of-government plan that is changing the way that human services are developed and delivered in the ACT. It is a long-term reform agenda to make the ACT's human services system more integrated, person-centred and sustainable. The human services system is the network of supports that respond to a person's needs, including services relating to public/social housing, health and wellbeing, education, disability, care and protection and justice (ACT Government, 2016b). This is a plan, developed by community and government, which will guide how services and supports are provided so that people get the best outcomes for their circumstances. The Human Services Blueprint is a major change in the ACT that involves many steps and many people. It will take time to introduce completely, and to work well. Therefore, the Human Services Blueprint has started with three initiatives under the name 'Better Services'. These initiatives include, a Local Services Network (in West Belconnen to support the community to work together to build services around it's needs), the Gateway (a single access point for a range of services, e.g. housing and tenancy issues, disability) and Strengthening Families (a way of working with families who have complex needs and who are involved with many difference services) (ACT Government, 2016b).

OneLink

OneLink is 'the Gateway' initiative of the Human Services Blueprint. It provides information and access to all human services in the ACT, being the access point for all homelessness services, including emergency accommodation providers, and works closely with child, youth and family services. A OneLink intake officer will provide information options and where appropriate follow up

to connect people with services, and stay in touch until people have the services they need (OneLink, 2016). While OneLink provides information and access to a range of community services, linking to health services, in particular primary health services, is not a key component of their service.

Strengthening Families

Strengthening Families is an ACT Government run service, which commenced as one of the flagship Better Services Initiatives (part of the Human Services Blueprint) (ACT Government, 2016a). The Strengthening Families approach is now delivered by Onelink, through a partnership with the Child, Youth and Family Services Program (CYFSP). The Strengthening Families approach is a family-centred way of working and is acknowledged as best practice in supporting families who experience multiple complex needs who are involved in many different services (ACT Government, 2016a). The key to the approach is that families have a Lead Worker who works alongside them, so the family has a single point of contact to support them in identifying strengths and problems. In most cases the lead worker is a case co-ordinator and does not undertake therapeutic intervention. Together, they develop an agreed family plan and put together a package of supports that best respond to their collective needs. Participation in Strengthening Families is voluntary and all family members can be involved.

The Strengthening Families practice approach is now in the process of being embedded more widely across all Directorates and community sector organisations, to become 'business as usual'. The key elements of the approach are:

- a family-centred approach that considers the needs of the family as a whole
- building family capacity by encouraging families to co-design and 'own' their support plans, to identify and achieve the goals that are most important to them
- establishing Strengthening Families Champions in each of the human services directorates, to support change and encourage solutions to address systems or service barriers

The Strengthening Families approach is a co-ordination rather than a therapeutic approach, which uses co-design to build families' capacity to manage their human services journey. This approach does not deliver social work case management required for families with complexity when engagement requires highly skilled interventions. The approach has key links with the human services directorates: Justice and Community Safety; Community Services; Education; and ACT Health. The outcomes of this approach are yet to be evaluated to identify impact of this service.

Despite these existing services operating in the ACT to support families with complex health and social care needs, many of these families continue to 'fall through the cracks' and are in need of

further and more longitudinal support. Further support for these families could potentially 'piggyback' on what already exists in the ACT.

Key Issues

Integration of health and social services

Care and support for families with complex needs requires close cooperation between the health and social care sectors. The separation of health and social care does not recognise some families' closely related needs for both types of care. The complexity necessitates a collaborative approach to ensure sustainable change, but there remain a number of barriers to overcome, including organisational silos, a lack of access to relevant and timely data and privacy and confidentiality issues.

Failure to integrate physical and mental health care also causes problems for families with complex needs. Care for mental health must be integrated with physical health care, with multidisciplinary teams ensuring that physical and mental health problems are addressed together.

Communication between providers

It is important that providers treating families with complex needs are able to share important data about the family as this ensures they have the information they need, when they need it. Also critical is good and timely provider communication, including prompt transmission of information to the GP following hospitalisation and specialist visits and the sharing of information and plans with after hours and emergency services.

Achieving the triple aim of improving quality, lowering costs and enhancing the patient experience can only be done with a significantly altered and improved communication strategy.

Support Coordination

Families with complex health and social care needs may find it very difficult navigating the health system and obtaining the care and support that they require. Support Coordination is part of the National Disability Insurance Scheme (NDIS) and is a capacity building support to implement all supports in a participant's plan, including informal, mainstream, community and funded supports. Support coordinators work with participants to determine how they utilise their support budgets to achieve their goals. This includes supporting the participant to choose preferred options or providers; negotiate services to be provided and their prices, develop service agreements and create service bookings with preferred providers; arrange any assessments required to determine the nature and type of funding required; link to mainstream or community services; strengthen and

enhance their capacity to coordinate supports, self-direct and manage supports and participate in the community (National Disability Insurance Scheme, 2017). The NDIS will connect people with disability, their families and carers, including people who are not NDIS participants, to disability and mainstream supports in their community.

A new program, Permanency Support Program, is being rolled out in October this year in NSW by Family and Community Services and is a good model of support for families with complex health and social care needs. This program has a substantial focus on comprehensive preservation work for complex families at risk and includes a comprehensive therapeutic and case management approach. The Permanency Support Program was developed in response to a review of the Out Of Home Care system in NSW, which concluded that the current system was not client-centred, was designed around programs and service models rather than the needs of vulnerable families and that poor outcomes continue after leaving care, which drives demand for Government services at significant cost (NSW Government, 2017). The new program introduces tailored support packages; an investment approach to service delivery and a single commissioning entity. The service model:

- provides funding to support the services required to deliver outcomes in the case plan
- will more clearly oversight case plan directions
- has case plan goals which are time bound (over two years) and linked to the provision of funding
- has a continuum of care created to support the delivery of non-placement supports
- has more investment up front to help families change and minimize entry and re-entry into care

Respite

Respite services provide planned short term, time-limited breaks for families and other unpaid carers of children, young people and adults with the intention that families/carers resume care at the end of the respite period. They are services that assume the caring role during the period of respite. Respite is one of a suite of services which supports families by providing short term breaks to the carer and other family members from care giving responsibilities.

There is a need for family members who are continually providing care and support for other members of their family, and are usually unpaid, to have regular time away from their caring role. This support may need to include respite care to provide relief for caregivers and assistance to help them look after their own health (Mossialos et al., 2017). Health services need to take steps to identify and support these informal caregivers.

Respite has a number of benefits, with the most consistently reported finding being that respite care has positive effects on family functioning, including parents and carers being able to spend time with other children, increased participation in social activities and decreased perceived family conflict (Merriman and Canavan, 2007).

However, a lack of secure facilities for children in the ACT has been identified.

Priority Issues

Need for better coordination of services for families with complex health and social care needs

Families with complex needs typically require not only a broad range of health services provided by diverse clinicians and health care institutions but also therapeutic home and community based services to overcome functional limitations and maintain independence. A family may be experiencing a number of issues relating to poor mental or physical health, financial hardship and finding support for a child with disability. This will involve contact with multiple services and a wide range of providers usually on a long-term basis and their care often becomes fragmented. This can result in more hospitalisations and lower patient satisfaction. Not only does this place considerable strain on public resources but there is little or no signs of improvement in the lives of these families. For this reason these patients need a dedicated person/case manager who is responsible for coordinating all their health and social care. This coordinated approach may also include a form of case conferencing for all identified agencies.

For support to work well, families need a single point of contact to assist them in identifying issues and to help coordinate the support that is needed. The Health Care Home is a promising model for providing comprehensive, coordinated care to families with complex health needs that often require regular support from health care services (Rich et al., 2012). The Health Care Home program is being developed by the Australian Government and is due to rollout in October 2017. While the ACT isn't a trial site, it is likely the Health Care Home model will be introduced to the area in the future. Some of the proposed principles underpinning the Health Care Home model include; patient and family centred healthcare, which acknowledges and supports cultural and social needs as well as engages patients as partners in care planning and design; a team-based approach to healthcare to include community-based organisations, mental health and other clinicians where appropriate; coordinated care across the system to reduce the fragmentation and improve coordination of patient care through their patient journey; and accessible, affordable, equitable and appropriate care (Thurecht et al., 2017).

Another strategy, developed in the UK, to address the needs of families with complex health and social needs is the model used in the Wakefield district in Yorkshire (NHS England, 2017). The Wakefield district has a population of around 333,759 people and they are registered with the district's 38 GP practices. Six GP practices have piloted the Multispecialty Community Provider program to test and deliver different models of care. One of the services included in this model is that of Care Navigation, where local people are being helped to access the care they need by more than 100 'care navigators' based in GP practices. Patients are helped to access the right care at the right time. From April to September 2016, the Care Navigation model helped to direct over 9,500 patients to other health, care and community professionals, apart from the GP, to receive the most appropriate care more quickly (NHS England, 2017).

Strategies

- The development of a whole of jurisdiction approach to the sharing of information between relevant providers/services supporting families with complex needs.
- Explore the feasibility and acceptability of using a 'care navigator' model based in general practices which can offer people/families, who arrive at the practice, help to access the care they need. These could be either:
 - support and administrative staff, who have the first contact with patients when they come into the surgery, are trained to direct patients to the most appropriate care (NHS England, 2017)
 - social work services in addition to the care provided by the GP and Allied Health providers (Sydney North Primary Health Network, 2017)
 - health leads (student volunteers) in GP practices who connect vulnerable families to local resources to meet their needs (Health Leads, 2017)

Identification of families with complex needs

It is crucial to identify families with complex needs and to assess the characteristics, needs and wants of the family prior to intervening. It is also important to gather information about a family from both the family themselves and other sources where possible (e.g. other service providers or case notes) and to identify and meet immediate needs for practical support and access to other services.

Strategies

- Support GPs and other primary health care providers to identify families with complex health and social needs and refer them to appropriate services.

GP advocacy for families with complex needs

The GP plays a key advocacy role for all patients and helps them access the care they need in an increasingly complex system. This advocacy role is particularly important for families with complex health and social care needs. The advocacy role of the GP includes:

- helping the patient and/or family to take an active part in the clinical decision-making process
- working with government, non-government and private organisations to maximise equitable services to all members of the community
- for disadvantaged/vulnerable patients, the GP is ideally placed to facilitate their access to other services and assist them in navigating the health and social system

Strategies

- Support GPs to play an advocacy role for families with complex health and social needs to facilitate these families' access to other appropriate services and assist them to navigate the health and social system as required.

References

- ACT GOVERNMENT 2012. Listening to Families: Understanding the journey of families through the ACT service system. Canberra: ACT Government, ThinkPlace.
- ACT GOVERNMENT. 2016a. *Better Services: Strengthening Families* [Online]. Canberra: ACT Government. Available: <https://www.betterservices.act.gov.au/strengthening-families> [Accessed 21 Mar 2017].
- ACT GOVERNMENT. 2016b. *Getting help from services in the ACT: the Human Services Blueprint* [Online]. Canberra: ACT Government. Available: <https://www.betterservices.act.gov.au/human-services-blueprint> [Accessed 26 July 2017].
- AUSTRALIAN INSTITUTE OF FAMILY STUDIES. 2016. *Child protection and Aboriginal and Torres Strait Islander children. CFCA Resource Sheet* [Online]. Melbourne: Australian Institute of Family Studies. Available: <https://aifs.gov.au/cfca/publications/child-protection-and-aboriginal-and-torres-strait-islander-children> [Accessed 2017 20 April].
- BROMFIELD, L., SUTHERLAND, K. & PARKER, R. 2012. Families with multiple and complex needs: Best interests case practice model, Specialist practice resource. Melbourne: Victorian Government Department of Human Services.

- HEALTH LEADS. 2017. *Health Leads* [Online]. Health Leads. Available: <https://www.bmc.org/programs/health-leads> [Accessed 2017 15 Sept].
- KATZ, I., SPOONER, C. & VALENTINE, K. 2006. What interventions are effective in improving outcomes for children of families with multiple and complex problems? Perth: Australian Research Alliance for Children & Youth (ARACY).
- MERRIMAN, B. & CANAVAN, J. 2007. Towards best practice in the provision of respite services for people with intellectual disabilities and autism. Galway: Child and Family Research Centre, National University of Ireland.
- MOSSIALOS, E. A., OSBORN, R., ROLAND, M., ABRAMS, M., AMELUNG, V., BALICER, R. D., BATTERSBY, M., ANDERSON, G., BOJESTIG, M., BUSSE, R., DURAND-ZALESKI, I., IKEGAMI, N., MEYER, G., PEARSON, M., RIJKEN, M. & SINHA, S. 2017. Designing a High-Performing Health Care System for Patients with Complex Needs: Ten Recommendations for Policymakers. The Commonwealth Fund International Experts Working Group on Patients with Complex Conditions.
- NATIONAL COMPLEX NEEDS ALLIANCE 2014. National Complex Needs Alliance: Position Paper. Canberra: National Complex Needs Alliance.
- NATIONAL DISABILITY INSURANCE SCHEME 2017. Support Coordination: Information for providers. NDIS.
- NHS ENGLAND. 2017. *Wakefield Connecting Care Multispecialty Community Provider* [Online]. NHS England. Available: <https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/community-sites/west-wakefield/> [Accessed 2017 16 Aug].
- NSW GOVERNMENT. 2017. *Permanency Support Program* [Online]. Family & Community Services, NSW Government. Available: <http://www.community.nsw.gov.au/about-us/key-reforms/permanency-support-program> [Accessed 16 Aug 2017].
- ONELINK. 2016. *Services* [Online]. OneLink. Available: <http://www.onelink.org.au/services> [Accessed 26 July 2017].
- PARKER, R. 2009. *Helping families with complex needs: Integration of the Strength to Strength and Resources for Adolescents and Parents programs. Family Relationships Quarterly, No. 14.* [Online]. Melbourne: Australian Institute of Family Studies. Available: <http://www.aifs.gov.au/afrc/pubs/newsletter/n14pdf/n14f.pdf> [Accessed 20 April 2017].
- RICH, E., LIPSON, D., LIBERSKY, J. & PARCHMAN, M. 2012. Coordinating Care for Adults With Complex Care Needs in the Patient-Centered Medical Home: Challenges and Solutions. White Paper (Prepared by Mathematica Policy Research under Contract No. HHS290200900019I/HHS29032005T). AHRQ Publication No. 12-0010-EF. Rockville, MD, USA: Agency for Healthcare Research and Quality.
- SOCIAL POLICY EVALUATION AND RESEARCH UNIT 2015. Families with complex needs: International approaches [In focus]. Wellington, NZ: Social Policy Evaluation and Research Unit.
- SYDNEY NORTH PRIMARY HEALTH NETWORK. 2017. *Commissioned Services* [Online]. Sydney: Sydney North Primary Health Network. Available: <http://sydneynorthhealthnetwork.org.au/about-us/commissioning/commissioned-services/#social-work-service> [Accessed 15 Sept 2017].
- THURECHT, L., WOOLCOCK, K., SILK, K., PARTEL, K. & VERHOEVEN, A. 2017. Health Care Homes: principles and enablers for their implementation in Australia. Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association.