



Government of **Western Australia**
Department of **Health**

Care Coordination for People with Disability

**Outcomes of a survey of Disability and Health
service providers**

**Disability Health Network
Care Coordination Working Group
Care Coordination Framework project group**

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Overview

An online survey of Western Australian health and disability service providers was conducted in early 2015 by the DHN CCWG, with the aims of exploring:

- Current use and understanding of the term “care coordination” within and across the sectors that provide support for consumer health and wellbeing (defined below)
- Current delivery of services named “care coordination”
- Current delivery of services that are not named “care coordination” but which may be considered to be care coordination under a standardised definition
- Gaps in provision of care coordination delivery as identified by service providers.

The aspect of care coordination of particular interest to the CCWG relates to coordination of health care. The responses revealed that “care coordination” is a term which is widely used, although with different meanings in different sectors. Care coordination is known to be a difficult term to define (Ehrlich et al 2009) and the survey responses demonstrate that any efforts to improve care coordination for people with disability should not rely on an assumed shared understanding; rather, the specific tasks of care coordination need to be specified.

Survey development process

The CCWG is comprised of representatives from a range of health and disability providers with a common interest in the coordination of care within and across the sectors. The group has developed a working definition of care coordination:

‘Care coordination’ can be broadly defined as the systems and processes in place to ensure that health care for people with disabilities is managed consistently across the continuum of care, including in-patient and out-patient hospital care, primary care, patient self-management/carer management and the community and residential care sectors. Central elements of care coordination include an effective transition of care including handover processes and care plans (communication), and a holistic perspective of the needs and preferences of the person.

This definition was further informed through a series of [Focus Groups](#) held with people with disability and family carers of people with disabilities in June 2014. Specific task themes of care coordination were identified by the contributing consumers, and these themes were incorporated into the survey in an attempt to specify the tasks of care coordination.

Support for consumer health and wellbeing was broadly defined for the purposes of the survey to include:

- inpatient, outpatient and emergency hospital care
- community nursing (such as wound care, oxygen therapy, continence management, stoma care)
- community physiotherapy and non-hospital rehabilitation
- primary care
- services which advise on, provide, and maintain aids and equipment which support health and function

- in-home, residential and community services which assist with maintenance of adequate nutrition, hygiene, medication management, pressure care, transport to health-related appointments
- disease management education and support including timely linkage of consumers to appropriate health care when there is a change in health status

The survey was made available on Citizen Space and widely shared through email distribution lists held by the WA Department of Health, Disability Services Commission and the networks of CCWG members in March 2015.

Outcomes

Service provider definitions of the term “care coordination” were varied and the term was not described in a standard way across or even within service areas. Nonetheless, a number of common themes could be identified in the definitions of care coordination provided by respondents. The primary theme was “service linkage”, with other themes clustered around “multiple service providers who work together”, “macro-level tasks and outcomes of care coordination beyond the individual client” and “interpersonal supportive approach to care delivery”. Care coordination was not generally defined as being specifically related to health care. Attempts to further clarify what care coordination means in different service sectors would benefit from auditing of specific care coordination activities and interventions.

Most service providers indicated that they provide a service called “care coordination” or aspects of what could be described as care coordination. This appears to be predominately in the areas of connecting people to services (e.g. making referrals) providing information and advice (such as which services are available) and assessment of care needs and preferences of people living with disabilities. Fewer respondents stated that their organisations offer a central point of contact for care coordination, coordinate health care appointments, or oversee all of health care received by people with disabilities. Interestingly, only one-third of respondents called these activities “care coordination”, with the majority using other terms such as “case coordination” or “case management”.

The vast majority of respondents indicated that they usually or always provided health care coordination activities for people with disabilities when it was needed. The main reasons given for not always providing health care coordination when it was needed were a lack of resources and skills, and that health care coordination was not a responsibility of the agency.

Respondents identified a range of strengths, gaps and opportunities in relation to care coordination. Based on these, a number of strategies which could improve the coordination of care for people with disabilities were identified. These include:

1. Person centred, flexible approaches to needs assessment and service delivery, rather than “one size fits all” models
2. Improved transitions of care between service providers
3. Improved access to information about available services
4. Training support in care coordination skills for staff working with people with disabilities
5. Include health care as part of non-health services
6. Increased funding for care coordination activities
7. Designated “key contact person” roles for care coordination within service providers
8. Better relationships between service providers within and across different sectors

When compared to the results of the CCWG focus groups with people with disabilities and carers, the survey of service providers suggests that there is a gap between some of the care coordination expectations of consumers and the services actually being provided. This is particularly so in the areas of providing a single point of contact (such as a key contact person) to coordinate care and the overseeing of all of the care that is being received to ensure that all of the needs of the person with disability are being met.

Two hundred and eleven respondents completed the survey. Although there was a broad range of respondents across the disability, community, hospital and primary care fields, the online survey method probably did not capture the full picture of the availability of care coordination for people with disabilities in Western Australia. Some service provider groups were noticeably absent from respondents (e.g. in-home service providers). Further, all respondents indicated a level of involvement in care coordination. This means that service providers that do not provide care coordination are not represented in the survey findings. To the extent that these organisations might want to provide care coordination but for some reason do not, the survey may under-represent gaps and opportunities for improvement in care coordination for people with disabilities.

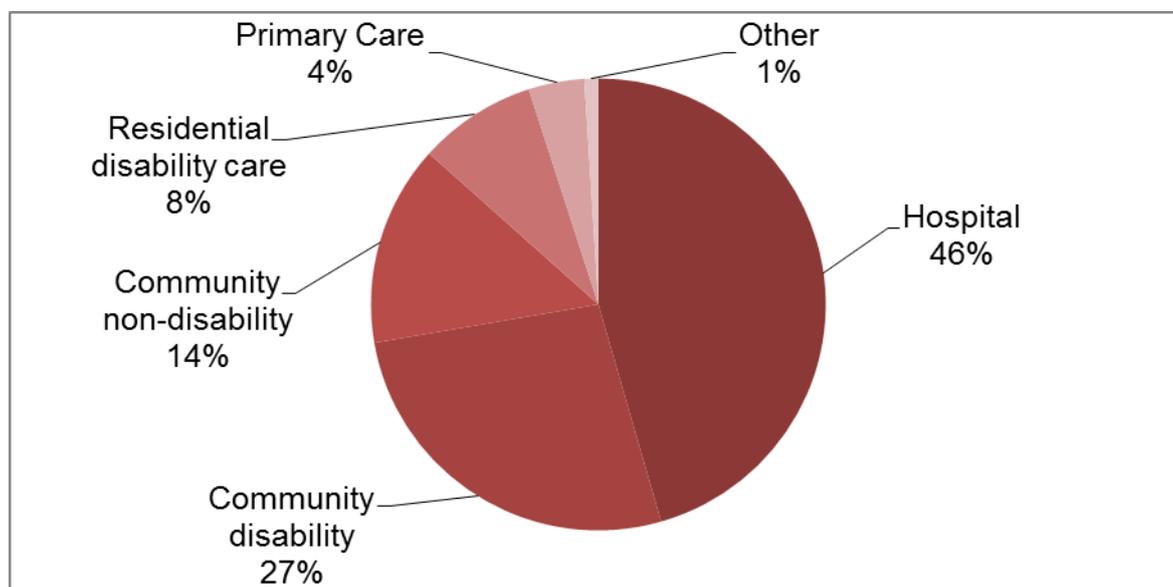
The results of the survey are discussed below in line with the survey format.

Section 1: Demographics

The purpose of the first section of the survey was to categorise respondents and gain an understanding of the range of organisations represented.

- 50% of respondents reported that they worked for a health organisation (46% 'Hospital' and 4% 'Primary Care')
- 41% of respondents worked for a community-based services provider (27% for a 'disability specific' service and 14% for a service which is not disability-specific)
- 4% of respondents worked for a provider of residential disability care
- Although included in survey distributions, there were no responses received from residential aged care providers
- 'Other' providers were Mental Health and Academic respondents

Chart 1: Organisations represented by survey respondents



The majority of respondents (72%) identified as working for a 'government' organisation. 25% identified as 'not for profit', 2% as 'private' and the remainder as 'academic'. They indicated that they worked with clients across all ages, with the highest representation (65%) for clients aged 18-64 years.

Respondents worked in a range of 'primary service/program' areas, with the most frequently arising areas being 'Allied Health/Therapy' (26%) and 'Social Work' (12%). Other areas included nursing/midwifery, accommodation provision, dedicated care coordination services, education/information/training, condition-specific services (e.g. acquired brain injury) and rehabilitation. Only 4% of respondents stated they work in the areas of 'support' or 'in-home services' which indicates that a key group targeted by the survey is not well represented.

Section 2: Understanding of the term “care coordination”

82% of respondents indicated that they had heard of the term 'care coordination' prior to the survey. In response to the question: "What does the term care coordination mean to you?", only 16% of respondents indicated that the care being coordinated is specifically healthcare; Primary Care respondents were most likely to link care coordination to health care (33% of respondents), followed by Community non disability-specific (19%), Hospital (17%), Community disability-specific (9%) and Residential care disability-specific (7%).

"I prefer the title 'support coordination' or 'coordination' as people with disabilities are not sick" – Community-based services provider – disability specific

An over-all theme of **Service linkage** was identified – being the task of identifying the needs of the individual client and arranging for corresponding services to be put in place. The remaining 18 themes can be divided into 3 clusters as below.

Cluster 1. Multiple providers working together, with or without central coordination

- **Coordinate all services** – awareness of and manipulation of all services involved (multiple agencies)
- **Case Management** – seen as an interchangeable term with Care Coordination and implying a dedicated position responsible for accessing and coordinating services
- **Team approach** – multiple players from the same team delivering care in series and with ongoing communication to effect efficient care delivery
- **Overcome fragmentation** – recognise the existence of other providers and working to enhance communication between them
- **Partnership to match needs to services** – a joint effort by multiple providers to work together to deliver the range of services needed by the client
- **Point of central contact** – person that client can contact regarding all of their care or all of the care from a specific agency

Cluster 2. The macro-level tasks and outcomes of care coordination – beyond the individual client

- **Internal service coordination** – the tasks involved in an agency delivering its care (allocation of staff to required tasks, managing processes)
- **Best use of resources** – ensuring that only people who require services receive them (gatekeeping)
- **Reduce demand on hospital** – activities seeking to prevent hospitalisation to save costs
- **“At risk”** – reference to the need to identify and target services to people who are “at risk”
- **Best care, outcomes and practice** – care coordination described as a way to ensure best care
- **Identify and quantify gaps** – studying the delivery of services to a client group and providing evidence of gaps to be filled

Cluster 3. Interpersonal supportive approach to care delivery

- **Provide information** – giving people with disabilities and their families information about available services
- **“Holistic”** – a number of responses included this term, generally without further explanation
- **Work along-side people** – decisions made by clients following education and support
- **Personal plans/goals** – responsibility for supporting clients to develop and work towards their own personal goals and plans
- **Support the person and family** – interpersonal supportive relationship and care for the client including their family system
- **Measure outcomes** – review delivery of services to individual client to ascertain whether current services are meeting need, or whether change is required

The theme of **Service linkage** was identified most frequently as a definition of care coordination for all groups except the community disability and community non-disability specific groups who also identified **Overcoming fragmentation** (within Cluster 1 above) with equal frequency.

Community Disability, Community Non-disability specific, and Hospital respondents all described the widest range of themes to define care coordination (each had 17 different themes). Community Disability described a higher number of comments under the interpersonal/supportive approach theme (Cluster 3), possibly consistent with agency culture and roles. Community Non-Disability described a higher number of comments related to tasks and outcomes (Cluster 2), reflecting likely responsibility of respondents in general assessment and delivery of specific funded services to a high number of clients. Hospital respondents defined care coordination most commonly with a focus on the coordination of multiple providers (Cluster 1).

Residential Disability and Primary Care respondents were smaller groups and demonstrated a narrower range of definition themes (10 and 11 themes respectively). Residential care providers focused equally on the coordination of multiple providers (Cluster 1) and tasks and outcomes (Cluster 2). Primary Care showed a greater focus on coordination of multiple providers (Cluster 1).

Section 3: Provision of care coordination activities and use of the term “care coordination”

Fourteen separate activities considered to be “health care coordination” (as identified through previous activities of the CCWG) were listed, and respondents were asked to indicate the activities that were delivered by their organisation. The tables below (next two pages) show all activities listed in the order of most to least frequently delivered (Table 1) and the most and least frequently occurring activities by each sector as reported by respondents (Table 2). Activities around assessment, referral, information provision and advocacy were the most frequently occurring; a central point of coordination, assistance with funding, oversight of health care and coordination of health appointments occurred least frequently.

Thirty-four percent of respondents indicated that they used the term ‘care coordination’ to describe the listed activities. Other terms used most frequently were:

- **Case coordination** (used across all sectors)
- **Case management** (used in Primary Care and Disability-specific Community Services)
- **Key contact person** (used in Disability-specific and Non disability-specific Community Services)
- **Discharge planning** (used in Hospitals)

The remaining terms used were generally specific role titles, for example “Clinical Nurse Specialist” and “Care Advisor”.

Ninety respondents named one or more activities which they considered to be health care coordination activities of their service or program area but were not covered by the 14 given activities. There were a total of 8 themes for additional activities:

- Specialty team assessment (10 responses)
- Delivery of rehabilitation (9 responses)
- Delivery of acute care (6 responses)
- Delivery of direct care and activity services (12 responses)
- Provision of equipment (7 responses)
- Discharge communication (1 responses)
- Service development and/or improvement (5 responses)
- Training of staff (2 responses)

The first five of the additional themes could be further summarised as “delivery of specific agency service”, indicating that care coordination is seen to occur not only between services but also within a delivered service. A similar theme was identified by some respondents in their definition of care coordination, namely **Internal service coordination** – the tasks involved in an agency delivering its care (allocation of staff to required tasks, managing processes).

Table 1.

Activity	% of agencies who state they provide the activity
Connect the person with disability, family and carer to appropriate services which support health and wellbeing (e.g. make referrals to these services or otherwise facilitate access)	93%
Provide information and advice related to health and wellbeing issues (e.g. what the person with disability, family and carer needs to think about, what help/aids are available, how to link services together)	92%
Undertake a process of assessment of needs which is “holistic” and seeks to identify all of the care needs and preferences of the person living with disability – including issues that require referral to other services to address	90%
Use your organisation’s knowledge of the health and disability systems to provide advice, advocacy and/or problem-solving related to health care and accessing required support for health and wellbeing	84%
Regularly communicate with other involved service providers and health professionals to share information about the person’s care requirements	80%
Advocate for the health care needs of the person with disability	77%
Participate in a “team approach” to care where different service providers work together and the person with disability and/or their carer is/are included as part of the team	76%
Participate in a “team approach” to care where different service providers work together	76%
Provide interpersonal support (e.g. counselling, listening, mentoring) to people with disability, their families and carers	73%
Develop health care plans, whether it’s part of a whole life plan/holistic care or not	65%
Have a person/role within your organisation who acts as a single point of contact to coordinate care for your clients as need arises, including health care	53%
Assist with funding (e.g. provide funding or help with writing applications for different agencies/funding sources)	53%
Oversee all of the health care that is being received, to ensure that all of the needs of the person with disability are being met (ongoing contact or regular reviews)	42%
Coordinate health care appointments for the person with disability, including those between multiple service providers	40%

Table 2.

Sector	Most frequently provided by respondents (Refer to Table 1 above for full activity description)	Least frequently provided by respondents (Refer to Table 1 above for full activity description)
Community-based services provider – disability specific	Connecting to services (92% stated that they provide this) Needs assessment (84%) Information and advice (84%)	Oversee all health care (40% stated that they provide this) Coordinate health care appointments (36%)
Community-based services provider – non disability specific	Needs assessment (96%) Connecting to services (96%) Knowledge of systems (93%)	Oversee all health care (59%) Coordinate health care appointments (56%)
Hospital	Needs assessment (95%) Information and advice (86%) Knowledge of systems (82%)	Oversee all health care (33%) Coordinate health care appointments (32%)
Primary Care	Information and advice (78%) Connecting to services (78%) Communicate with other service providers (78%)	Single point of contact (44%) Oversee all health care (44%) Assist with funding (44%) Interpersonal support (44%)
Residential Care (disability care)	Needs assessment (100%) Connecting to services (94%) Information and advice (88%) Interpersonal support (88%)	Assist with funding (56%) Team approach with person with disability (69%) Single point of contact (69%)

Most respondents (71%) stated that they “Always” or “Often” provide health care coordination for people with disability when it is needed. Reasons for not providing health care coordination were:

Table 3.

Reason for not providing health care coordination	% of respondents
Health care coordination is not the role of my service or program area	18%
We do not have the staffing resources to provide health care coordination	17%
Lack of time	16%
Not enough funding	12%
Our staff do not have the skills to provide health care coordination	6%
Difficulty sharing information outside my service/program area	6%
Not needed or not wanted by clients and/or families	6%
Geographical issues (e.g. clients live in rural or remote areas)	5%
Not all people with disabilities meet our criteria	2%
We refer this issue to another service	1%

Forty-six percent of respondents were not able to name any services which provide care coordination when asked to “Name any other health or disability services, programs or organisations are you aware of which provide health care coordination”. The remaining respondents contributed over 50 named agencies or general service types, however it appeared that “health care coordination” had been conflated with “agencies which provide services to people with disabilities”.

Disability Services Commission Local Area Coordinators were the most frequently arising service provider identified by respondents as providing health care coordination, although 5 respondents commented that Local Area Coordinators do not provide this service or have limitations on providing this service. Respondents employed in *Primary Care* were the group most likely to identify Local Area Coordinators as health care coordinators (55% of respondents) followed by the *Community based services – not disability specific* sector (30% of respondents).

Seven broad categories of services that provide care coordination have been drawn from the responses. Each is shown below, with the 3 most frequently named services. A list of all of the services identified is provided in Appendix 2.

1. Disability Services Commission funded and developmental disability services
 - Disability Services Commission Local Area Coordinators were the most frequently arising service identified as providing health care coordination within this category (41 respondents)
 - Ability Centre (formerly Cerebral Palsy Association) was identified by 11 respondents
 - Rocky Bay was identified by 8 respondents

2. Primary health care services
 - A chronic disease management plan completed by a General Practitioner or Practice Nurse was identified by 5 respondents
 - Medicare Locals were identified by 3 respondents
 - Chronic disease coordinators were identified by 2 respondents
3. Hospital Services
 - CoNeCT was identified by 18 respondents
 - Hospitals were identified by 14 respondents (both hospital and non-hospital respondents)
 - Specialist tertiary clinics were identified by 4 respondents
4. Aged care/non-disability specific community and residential services
 - The general category of provider of funded aged care services, or a specific named HACC or HCP provider, was identified by 31 respondents
 - Aged Care Assessment Teams were identified by 10 respondents (predominately identified by Hospital respondents and Primary Care respondents)
 - Regional Assessment Service (HACC assessment) was named by 3 respondents
5. Condition-specific support and information services
 - MS Society (multiple sclerosis) was identified by 4 respondents
 - State Head Injured Unit was also identified by 4 respondents
 - Neurological Council was named by 3 respondents
6. Mental health services
 - Community Mental Health was identified by 12 respondents
 - Partners in Recovery was identified by 5 respondents
 - Ruah was identified by 2 respondents
7. Family, employment and welfare services
 - Department for Child Protection and Family Support was identified by 4 respondents
 - Six other community based child and family support, migrant support and employment support organisations were identified

Section 4: Gaps, Strengths and Opportunities for improvement in care coordination

Gaps

Respondents to the question “In the health and disability sectors, what gaps, if any, do you see in the provision of health care coordination for people with disability?” took the opportunity to discuss a wide variety of perceived gaps in the care of people with disabilities, including issues not related to health or to care coordination as defined.

Five key themes were identified relating to gaps in health care coordination for people with disability:

Transitions and relationships between service providers

This refers to poor care transitions which were characterised by a lack of communication, collaboration or information sharing between service providers. Transitions included acquisition of a new disability, movement through paediatric to adult and disability to aged care sectors, discharge planning, and processes involved in setting up services (78 responses).

Funding

Insufficient funding available to provide needed services (36 responses).

Complexity

The health and support systems are too complex or unknown for people with disabilities to be able to self-coordinate and there is no one to take this role (34 responses).

Staff

Health and support service providers lack the skills and knowledge required to work with people with disabilities (28 responses). Also, attraction and retention of skilled staff in community sectors is an issue and impacts on quality of service (7 responses).

Commitment to health care coordination

This relates to a lack of will, direction, support and/or skills for agencies to provide care coordination (14 responses). It also refers to a lack of attention to health issues by disability and community sectors (8 responses) and an emphasis being placed on acute care and not on preventative or chronic health care (10 responses).

Strengths

Respondents were asked “In terms of providing health care coordination for people with disabilities, what are the strengths of your service or program area?”. Each of the following was mentioned as a strength by at least once by respondents in every organisation type, except where noted below.

Person-centred approaches.

This was also referred to as patient-centred, consumer-directed and client-focused. Involves “individualised service design and delivery”, being responsive to and basing care on individual needs/goals and having an ongoing relationship/partnership with the client/family. It means

having personal knowledge of the person with disabilities. It is related to the strength of flexibility in service delivery, that is, being adaptable, creative, thinking outside the box to meet client needs and not using a 'one-size fits all' model.

Holistic care.

This involves taking into consideration multiple domains of a person's life in making assessments, referrals and coordinating their care. These domains could include medical, physical, functional, psychological, cultural, social/relationships/networks, lifestyle and emotional well-being. It also involved adopting family-centred care/practice models (e.g. a "family systemic approach").

Multi-disciplinary team approach.

Also referred to as trans- and inter-disciplinary teams that include a range of allied health and nursing staff and in the hospital setting also clinicians and discharge coordinators. Further in hospital settings, the social worker was seen as a key member of teams that have the best approach to care coordination.

Staff.

Perceived strengths included having staff with expertise and who were experienced (across a range of disabilities), knowledgeable, highly qualified, highly skilled and well-trained. Staff were perceived to have good communication skills and be approachable, responsive, motivated, keen to help and have a belief in care coordination.

Communication.

Clear internal communication between staff involved in a patient's care was valued. Also important was good communication with the patient/client and this includes having a single point of contact such as a dedicated coordinator or designated key worker; a specific 'go to' person who could provide advice, action, care planning and support.

Relationships with other service providers.

(Mentioned by all except primary care respondents).

Good communication, sharing information, engaging, building relationships, networking and collaborating with other service providers, particularly those local to the patient/client, were also perceived to be strengths. This included developing contacts in larger organisations and connecting with Local Area Coordinators (LACs). Such partnerships with a range of service providers (e.g. healthcare, rehabilitation, primary care/GP, support groups, non-government organisations) "help bridge the divide between hospital, community and disability interfaces" and enable the build-up of good knowledge about the systems, structures and services of service providers.

Planning.

(Mentioned by all except primary care and residential care respondents).

This can take the form of plans to set goals, priorities, strategies, lifestyle decisions, timeframes, weekly healthcare checks, annual/ongoing/regular reviews and regular follow-up updates. These were variously called "management plans" or "care plans". In the hospital setting, planning also included assessments, having clear referral pathways and discharge planning.

Management support.

Respondents from hospitals and disability-specific community organisations saw having senior/executive/management level support for care coordination as a strength.

Evidence-based practice.

This was seen as a strength by respondents from disability and non-disability specific community organisations and hospitals.

Opportunities for improvement

The opportunities for improvement in terms of providing health care coordination for people with disability that were identified by respondents were:

Funding

Increased funding was seen as a primary means of improving care coordination services. It was perceived that funding would enable the employment of more staff which would have effects such as smaller patient loads and being able to increase the number of clients. It would also enable greater proactivity by being able to respond more quickly to needs, wait lists and planning and allocating staff to see service users.

More staff/services

This involved being able to provide the services of a greater range of health professionals such as a counsellor, help-line health professional, therapy services, carer resource person, home visiting and a Key Therapist role. It also referred to expanding services geographically, particularly to regional, rural and remote areas, so that local services could be provided.

Training

This included training about care coordination and the impact of disability on health and wellbeing. This will increase staff skills in care coordination.

Improved communication, information-sharing and links between stakeholders

Networks, partnerships, inter-agency co-ordination/integration were viewed as critical to improving care coordination, between a range of stakeholders including disability service providers, health care providers (including hospitals, primary care/GPs, community health), patient support organisations, researchers/academia and government agencies such as WA Health, Mental Health, Disability Services Commission, Department for Child Protection and schools.

Greater awareness of services available

This involves knowing what is offered for people with disability and keeping abreast of new and changed programs/services. A resource list of available services for each type of disability was proposed. It was also suggested that the range of pathways for care in the community needs to be identified and understood.

Access to mental health services

Different services mentioned included psychiatric, neuropsychology, clinical psychology and community mental health.

Designated care coordinator role

This, or the allocation of more time to care coordination activities, was particularly seen as important in the hospitals/public health system and was perceived to save time and decrease risks. Reference was made by a primary care respondent to the need for a Key Worker Model of Service which involves a person who acts as a single point of contact and helps coordinate care within healthcare system and across other systems (e.g. education, social services, financial services, recreation and transportation).

Inclusion in documents

Care coordination for complex clients and clients with disabilities needs to be included in strategies, policies, procedures and practice guidelines.

Hospital specific organisational changes

Respondents from hospitals mentioned a variety of changes that could be made to improve care coordination. These included:

- Clearer, more formalised pathways for transition care (e.g. from Area Health Service Central Coordinators to DSC or child to adult services) including a point of contact/reference.
- Create a platform for LAC or other community coordinators to provide input during hospital admissions of people with disability
- Access to information on what other services the patient is involved with
- Have a more holistic view of health concerns, not just admission health concerns, and understanding of the complexities.
- A booklet or electronic device that includes all the patients' information
- Attendance at family meetings
- Greater communication with patients and carers
- Documentation of system process for families
- More health care information on specific conditions
- Improved governance of care coordination activities
- Adjusting to changes in the sector that will result from NDIS
- Support to implement Quality Improvement outcomes
- Better communication between staff
- Reduced paperwork (it takes away from clinical time). Others wanted more time for professional development and administration
- Improved culture of patient-focussed care
- Improved models of care that include care coordination
- Permanent funding of Disability Liaison Officer service (a current project)
- More multi-disciplinary care, home visits and coordination of hospital services

Non-disability specific community organisations: Changes mentioned by this sector included:

- Co-location of services
- Better planning and assessment tools
- Better communication pathways
- Regular team meetings

Section 5: Discussion and further planning

The intention of the survey was to identify the current understanding and delivery of care coordination by the broad range of providers of health and support services to people with disabilities in Western Australia. Survey respondents were individual members of staff who were presumably motivated to complete the survey due to interest in the topic and/or to the broader issue of community support for people with disabilities. Although the survey was widely distributed, responses were not received from all possible service providers, nor from all staff within the represented organisations. Responses therefore do not necessarily represent the complete picture of what care coordination is considered to be, or who does or doesn't provide it.

What the responses do show is that "care coordination" is a very broad term which can be understood to refer to a variety of activities across and within the different sectors of health and disability support care. This is consistent with related literature on the broader concept of general health care coordination (Powell Davies et al 2006; Ehrlich et al 2009). Respondents to the survey indicated that these activities can include:

- Providing information about service options and assisting people to make decisions about what they need and want
- Assessing eligibility for and making referrals to external or internal services
- Organising delivery of an agency's own services, including services delivered on a team basis
- Facilitating communication between multiple service providers working with the same client
- Acting as a central point of contact for either the provision of services by the agency, for the client requiring problem-solving/practical/emotional or other support, or as a navigator through complex systems

A basic shared definition of care coordination as "connecting clients with services" (described earlier as "Service Linkage") appears to exist across sectors and professions, however it is recommended that any analysis of services provided under the banner of care coordination should be careful to specifically define the activities of interest. In particular, it should not be assumed that the "care" being "coordinated" necessarily includes health care – services such as cleaning, shopping and recreation support may also be considered to be "care".

With such a broad range of possible definitions, it is not surprising that a high number of respondents (98.6%) indicated that they provide a form of care coordination. As per table 1 above, there were forms of care coordination provided to the respondents which were reported to occur less frequently – these are shown below in Table 4.

Table 4 also shows the 3 key themes identified by the CCWG Focus Groups (consumer) attendees as being the important aspects of care coordination. Two of the three key aspects of care coordination (from the point of view of the consumers who attended the Focus Groups) correspond to the aspects of care coordination reported by respondents to be less frequently provided.

This appears to indicate a potential gap between perceived care coordination needs of consumers and the actual care coordination activities being delivered in the health and disability sectors. The CCWG will seek further opinion from people with disabilities, carers and service providers on this issue.

Table 4

Less-often provided care coordination (via survey respondents)	Key aspects of care coordination identified by consumers (via Focus Groups)
<ul style="list-style-type: none"> • Have a person/role within your organisation who acts as a single point of contact to coordinate care for your clients as need arises, including health care • Oversee all of the health care that is being received, to ensure that all of the needs of the person with disability are being met (ongoing contact or regular reviews) • Assist with funding (e.g. provide funding or help with writing applications for different agencies/funding sources) • Coordinate health care appointments for the person with disability, including those between multiple service providers 	<ul style="list-style-type: none"> • Providing a central point of contact for problem solving and using “insider” knowledge of health and disability systems to provide advice, advocacy and problem solving • Overseeing all of the care that is being received to ensure that all of the needs of the person with a disability are being met • Facilitating communication between service providers to deliver care in a “team approach” – where the person with a disability and/or their carer is included as part of the team

A number of suggestions for improving care coordination were made by respondents across sectors. These have been summarised below- including reference to any known existing activities being undertaken by Disability Health Network and other project groups currently.

Suggested improvements to enhance care coordination across the health and disability sectors:

1. Needs assessment and service delivery approaches to take a “person centred”, flexible approach

“Person centred” care was defined by respondents as being responsive to and basing care on individual needs and goals, and on having an ongoing relationship/partnership with the client/family. Lack of staff continuity in hospital-based care pathways presents a particular challenge to the development of ongoing relationships; the Complex Needs Coordination Team (CoNeCT) has been a limited example of a hospital program which seeks to provide a central relationship to facilitate integration of care.

Assessment processes which can identify what an individual and their support system requires, and how their needs and goals can best be met, are crucial to the delivery of appropriate care. A “one-size-fits-all” approach which neither enquires into need nor has capacity to deliver flexible care creates a barrier to service access and effectiveness.

National Disability Insurance Scheme trials have commenced in Western Australia and they include development of personalised care plans for the delivery of community based and residential care. However, it is unclear whether health care is within the scope of assessment and planning processes.

2. Improve transitions of care

Respondents commented on the fragmentation of care services, particularly within health care and at times of transition between service providers, and the need for improved communication and collaboration between sectors. People with more complex needs, as may be the case for people with disabilities, may be placed at high risk of harm from poor care transitions.

The transition from paediatric to adult health care for people with disabilities has been identified as a particular area of interest by the Disability Health Network, with a discussion paper pending. Also pending is a trial of a communication tool for improved communication between providers of Group Homes/disability-specific accommodation and the acute health sector.

Personalised controlled electronic health records, although not well integrated to date and not inclusive of community service providers, has potential to improve transitions of care through improved access to information.

3. Make it easier to find services

Related to the definition of care coordination as the linking of people to services, respondents indicated a sense that the range of services potentially available to support people with disabilities is vast and yet people may not receive what they need due to a lack of knowledge of what is available and how to access it.

Individual agencies or staff within agencies, for example Social Workers in hospitals or Local Area Coordinators in the Disability Services Commission, develop and maintain resource libraries based on available service directories and their own networking and resourcing in the course of their roles. The Commonwealth Carelink and Respite Centres, still operating but now only providing the respite service previously maintained a database of local community providers which could be accessed either electronically or via telephone contact with local Carelink centres. The [My Aged Care](#) website provides limited database information on aged care services, which in some cases are also relevant to people with disabilities.

4. Training support and upskilling of staff who work with people with disabilities

In sectors which are not disability-specific, staff may have reduced skills and knowledge in providing their service in a way that can meet the care coordination needs of different people with disabilities. A desire among staff for more education in this area was evidenced in this survey and earlier through the Disability Health Network [Disability Liaison Officer scoping project](#) - a working group of the Network has been tasked with progressing this issue.

5. Include health care as part of non-health services and include preventative care

The delineation between “health” and “disability” services can be blurred, for example a medication service to prompt someone with a cognitive disability could be viewed as both. In comments, some respondents raised the concern that supporting the health needs of people with disabilities may not be seen as an area for input by providers of community/disability care. A provider of residential disability care commented that although residential staff had the skills to intervene in health issues, they were obliged to refer health issues to the primary care or hospital sectors. It was also mentioned by several providers that health care for people with disabilities tends to be focused on response to acute issues rather than on preventative health care. A planned review of key agencies reported in this survey to provide care coordination, will include further data collection on this topic.

6. Increase funding

Monetary resource was ultimately identified by respondents as a barrier to care coordination, with the related issues of lack of staff, lack of time, and lack of executive support to undertake a care coordination approach. Ehrlich et al (2009) note both that providing care coordination is more expensive due to being more time consuming, and that it can also increase overall service costs through identification and addressing of unmet need.

7. Designated “key contact person” roles

A role within service providers that is dedicated to care coordination could provide a single point of contact and help coordinate care within the health sector and across other sectors. In line with this, the Key Worker Model of Service could be further explored in the Western Australian context and specifically in relation to care coordination for people with disabilities.

8. Better relationships between service providers within and across sectors

In relation to care coordination, a number of potential improvements in the relationships and links between service providers were identified by survey respondents. This included better two-way communication and sharing of information. Ways in which this could be achieved include networks, partnerships, formal collaborations and inter-agency coordination. This would help “bridge the gaps” between service providers in health, community and disability sectors.

Conclusions

Findings from the survey relating to the understanding of care coordination for people with disabilities are consistent with evidence regarding health care coordination with the aged, people with mental health diagnoses and people with chronic health conditions (Powell Davies G, 2006). “Care coordination” is a simple term which describes varied activities which appear to align with the type of care provided by the provider of care.

As stated by Ehrlich et al (2009), caution should be exercised in viewing care coordination as being the simple answer to a complex problem. Nearly all of the respondents indicated that their agency provides care coordination, however on further review gaps in care remain. The suggested improvements above represent both the recommendations of the survey respondents, and examples of achievable actions to improve care coordination for people with disabilities.

Further action planned by the Care Coordination Working Group

The next activities of the CCWG will focus on identification of key care coordination skills utilised by agencies identified as being providers of a broad range of care coordination activities, and on further data collection to identify key gap issues in health care coordination as identified by people with disabilities.

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- Ehrlich C, Kendall E, Muenchberger H, Armstrong K (2009) *Coordinated care – what does that really mean?* Griffiths Institute of Health & Medical Research.
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- Russell L, Doggett J, Dawda ,P Wells R (2013) *Patient safety – handover of care between primary and acute care*. Australian Primary Health Care Research Institute, Australian National University.
- Stokes B (2011) *Review of admission and discharge referral practices for the metropolitan hospital emergency departments*. Department of Health, State Government of Western Australia.

Web links

Page:

- 2 Consumer Focus Groups – Care Coordination for People with Disabilities report
http://www.healthnetworks.health.wa.gov.au/docs/DHN_Care_Coordination_Consumer_Focus_Group_Report.pdf
- 18 My Aged Care
<http://www.myagedcare.gov.au/>
- Disability Liaison Officer scoping project
http://www.healthnetworks.health.wa.gov.au/docs/DLO_Project_Phase_1_Report.pdf

Appendices

Appendix 1: Names of organisations

(Optional question)

Organisation name	Total
Ability Centre	2
Aged Care Assessment Team	2
Autism Association of Western Australia	1
Baptist Care	1
Bentley ACAT	1
Brightwater Care group	4
Brookes Counselling Service	1
Care Net Community Nursing	1
Central Institute of Technology	1
Child and Adolescence Health Service (Princes Margaret Hospital)	11
Community Support and Rehab Program	1
Disability Services Commission	21
Enable Southwest Inc	1
EPIC empowering people in communities	1
Fiona Stanley Hospital	2
i.d.entity	2
Inner city tertiary hospital	1
Interchange	1
Kids' Camps	1
Lady Lawley Cottage	1
Mandurah Disabled Support and Recreational Respite Inc.)	1
Multiple Sclerosis Society	4
Neurological Council of WA	2
North Metro Health Service (Royal Perth, Swan, Osborne Park, Graylands, KEMH, SCGH)	24
Nulsen Disability Services	1
Nutrition and Diet Therapy Department	1
Panorama Health Network and Perth North Metro Medical Local	2
Parkinson's WA Inc.	1
Perth Central and East Metro Medicare Local	1

Organisation name	Total
Ramsay Health	1
Rehabilitation in the Home Program	1
Rocky Bay	2
Silver Chain	2
South Metro Health Service (Bentley, Armadale, Fremantle, Rockingham)	13
State Head Injury Unit	4
The Complex Needs Coordination Team, "CoNeCT"	2
Therapy Focus	1
Tuberous Sclerosis Australia	1
University of Notre Dame: MyLifeMyVoice.org (Teen NMD Study) Institute of Health Research	1
University of Western Australia Podiatry Disability Service	1
Upper Great Southern Family Support Association Inc.	1
WA Health	2
WA Country Health Service	17
Warren Blackwood Community Health Care Unit	1
Wheatbelt Individual and Family Support Association Inc. (trading as Ability Focus Wheatbelt)	1
Total	147

Appendix 2: Agencies named as providing care coordination

Disability Services Commission funded and developmental disability services

- Disability accommodation services
- Disability Services Commission/DSC Local Area Coordinators/NDIS
- Rocky Bay
- Abilities Centre (Formerly Cerebral Palsy Association)
- Therapy Focus
- Autism Association
- Senses
- My Place
- Nulsen
- General disability service/NGOs
- Private disability providers
- Activ
- VisAbility
- Bridges
- Community Living Association
- Life without barriers

Comments:

- Most community based services...provide a care coordination approach, only DSC don't
- LACs do their best
- Limited to country autism and the lacs
- Within business hours. Unfortunately crises are not limited to business hours
- unsure of LACs focus on health coordination or service coordination

Primary Care/Medicare funded

- Includes 2 services specifically for Aboriginal people and 2 remote area services
- Medicare Locals
- Care Plan GP/practice nurse
- Men's Health programs
- Aboriginal Health Service
- GP links
- Medibank and HBF pilot
- Remote area nurses
- Royal Flying Doctor Service

Mental health services

- Richmond Fellowship
- Partners in Recovery
- Community Mental Health/Mental Health Services
- Mental health inpatients
- RUAH

Hospital services

- Patient Assisted Travel Scheme
- Complex Needs Coordination Team (CoNeCT)
- Princess Margaret Hospital Mental Health Ambulatory Care Coordination and Paediatric Palliative Care
- Community Aids and Equipment Program
- Community Physiotherapy Program
- Community Rehabilitation/allied health day therapy
- Rehabilitation in The Home
- Hospitals – includes Emergency Department and Allied Health Care Coordination Teams
- Specialist tertiary clinics

Comment:

- [CoNeCT] limited number of clients

Aged care/non disability-specific community and residential services providers

Funded programs/providers

- Amana Living
- Brightwater
- Perth Home Care
- Home Care Packages
- Silver Chain
- Home and Community Care (HACC)
- Uniting care

Private providers

- Private provider
- Bluesky Health care
- Carealot
- Ray Village

Assessment and general information and support services

- RAS
- Aged Care Assessment Teams (ACAT)
- Commonwealth Carelink
- Carers WA
- Independent Living Centre

Condition-specific support organisations

- Cancer Council
- Cancer Nurse Coordination
- Neurological Council neurological nurses
- Neurosciences Unit
- Parkinsons Disease Association
- Multiple Sclerosis Society

- AIDS Council
- Spine and Limb Foundation
- Huntingtons WA
- Arthritis Foundation
- Alzheimers Association
- State Head Injured Unit

Family/employment/welfare/other

- Department of Child Protection
- Strong Families
- Education Department
- Refugee services
- Interwork
- Education and vocational centres
- Sport and leisure groups
- Housing NGO



This document can be made available in alternative formats on request for a person with a disability.

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