The State of Play
in Human Service Mapping
Services accessed by people with a disability

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"Reality is frequently inaccurate." – *Douglas Adams*

Disclaimer

Although there have been attempts to source funding for mapping disability services over many years – these have been unsuccessful. We have provided examples when possible but used in the main the further advanced mental health sector (Australia) and international examples.

The language used in sections of the report, reflect the service categories mapped (e.g., outpatient, day care, non- acute) and may seem to be very hospital-centric and even archaic for advanced community-based disability health and social support services which are already person-centred and highly developed. These reference terms only reflect the category nomenclature employed within the international classification systems of reference rather than a description of services.

Suggested Reference

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Key Findings

- Service mapping is a rapidly evolving area, already offering exciting potential to better plan, manage and deliver services.
- There is huge variability in the conceptualisation and definition of “service mapping”, ranging from simple geospatial location of service directories to highly advanced decision support systems for efficiency-informed and value-driven planning as well as for improving the health and social support service navigation experience of consumers.
- We argue that a formalised multistep, building blocks strategy should be adopted to develop a workable and useful toolkit instead of a single tool fit for all. This is because no single mapping tool can answer all decision, provider or user questions. We put forward a ‘mapping toolkit’ containing seven tools for mapping, visualisation and supporting decision making and planning for the National Disability Data Asset (NDDA).
- We note two concerns moving forward:
    - In Australia, we are limited by the data and system designs currently available to generate the maps themselves. Tools are only as effective as the data they are manipulating. These data limitations need to be addressed, including in relation to data type, infrastructure/design and linkage, if we are to capitalise on the potential of service mapping to support decision making in human service planning particularly focusing on people with disability.
    - There is a gap between a generalized demand for highly advanced decision support and navigation tools that could answer all the major questions of planning, access and delivery; and the difficulty in establishing a multistep strategy with a clear prioritization plan of the phases, processes, timing and outputs to achieve this ultimate goal.
- In presenting this toolkit, we recognise that the needs of the NDDA are emerging and evolving and the modules of the toolkit should be adapted to these needs. Mapping, visualisation and modelling have potential. It is open and flexible but over time, dependent on data availability, it can accommodate this evolution to create more useful and tailored products.

1. Introduction

This paper was commissioned by the New South Wales (NSW) Department of Premier and Cabinet, as part of the National Disability Data Asset to better understand how service mapping can support decision-making related to human services but focussed on services accessed by people with disability. The NDDA team engaged the Australian and New Zealand School of Government (ANZSOG) to work with the Centre for Mental Health Research, Australian National University (ANU) and the Centre for Social Impact, University of New South Wales (UNSW) to outline the current state of play and potential use of service mapping for people with disability in Australia.

This paper assists in enabling decision-makers to consider new and better ways to ensure people get the services they need, bearing in mind resource constraints. It is worth noting at the outset that service mapping is difficult, particularly in areas of human service like disability. However, it also has significant potential to support decision-making by providing information about service gaps, thereby reduce uncertainty, improve planning and end user experiences as well as enabling governments to address issues such as inequity in service access or quality.

This paper highlights the value and potential of service mapping, provides an overview on the current 'state of play' in relation to service mapping and the factors influencing service mapping quality and utility. We illustrate a possible "Decision Support Toolkit" with the combined use of five functions and these six tools. For each of the six tools, we briefly describe the functions, potential of the tool for decision-makers and service users, data source requirements and limitations; 'new' information or perspectives the tool provides, and potential uses in decision-making; limitations and for two we provide a case study/example of use. We have selected these six tools due to their demonstrated practical use and the existing published evidence that supports its use in Australia and overseas. We are aware that many more tools are available and could be incorporated into a multimodal decision system.

Finally, we underscore considerations for further work to realise the potential use of service mapping in Australia.

2. What is the frame of reference which underpins service mapping?

Person and people-centred health and social services is at the heart of recent attempts to improve the quality and responsiveness of services for people with a disability. In this section, we first outline the characteristics of person-centred health and social support systems and services. Second, we describe potential characteristics of a service map that is person-centred, and which enables the user/s to gain a perspective of person and people with a disability, health and social services.

Person-centredness refers to the individual ('person' at the levels of the micro and meso services and systems) and population ('people' at the level of meso and macro systems) [1]. Thus, the adjective 'person-centred' as it applies to systems analysis could be confusing as it does not reflect the population-based information within a service map. The preferred term is 'person and people centred care'. Box 1 provides the four key areas of micro to macro system characteristics of person and people centred health and social services.

Box 1. Micro to macro system characteristics of person and people centred health and social support services [1]

Four key areas:

1. A holistic approach to health conditions, based on the internationally accepted biopsychosocial model. This model is codified in the WHO International Classification of Functioning, Disability and Health (ICF) [2] . In the ICF the critical domain for people with a disability is the interaction of contextual factors with the health condition and subsequent impairments.

   > *Context entails environmental factors, including products and technology, environmental modifications, support and relationships, attitudes of family/ providers/employers, and personal factors such as age, socioeconomic background, education. Whether these are barriers (or facilitators) to individual functioning determines the level of disability, activities and participation.*

2. Empowerment of the person based on human rights embodied in the UN Convention on the Rights of Persons with Disability (UNCRPD) [3]. The attributes of PPCHC emphasises equality, needs based support services, and the involvement of people in their own health, social supports including decisions.
3. Integrated care and universal access – whereby integration has developed beyond coordination and collaboration between services for the person (vertical integration) to inclusion, participation and community-based supports, engaging the person and assessing personal factors such as quality of life and planning for solutions.
4. Complexity and context dependence – referring to the fact there is no single model for PPCHC because each context at the micro to macro level is different, although there can be a common framework.

There are international examples of system level change towards person-centred care and support services in systems comparable to Australia. However, not all system changes necessarily embody the key characteristics of PPCHC – holism, empowerment, integration and complexity.

The advancement and implementation of PPCHC systems and structures depend on enabling the co-production of care, shared knowledge and decision making, including the co-design of changes to improve the safety, quality and outcomes of health and social service delivery. Expressions of shared knowledge and decision-making that contribute as *key facilitators* for PPCHC include:

- A sentinel approach to lifelong health care
- The person having expert knowledge of their own situation, self-management and peer support
- Locally relevant person-centred primary and community care
- Investment in information communications technology development
- Inter-sector interaction, collaboration & partnerships

Another key challenge underpinning a true person-centred approach is the systemic capacity to properly assess individual functioning for needs assessment. We know this is currently an area where systems often struggle to clearly define, understand and respond to a person's needs.

What is the value of service mapping?

A "map of services" is a directory of services available in a jurisdiction together with its geographical location. The primary function of service mapping is descriptive, and its value is to inform consumers, carers, professionals, planners and other stakeholders about service availability and access to facilitate care and support service navigation, planning for support services and monitoring. The secondary value of service mapping is to provide key information to higher levels of analysis such as in service design (e.g., co-design from a person-centred approach), service quality (benchmark and organisational improvement), service efficiency, and causality (e.g., the relationship between service reform and improvement of results and outcomes). These higher levels of analysis require other tools apart from service mapping which can be combined into **Decision Support Toolkits** for planners, or into **Navigation Tools** for consumers, carers and professionals.

Table 1 (below) provides an outline of the various functions of the six tools illustrated in this report.

Table 1

FUNCTIONS	TOOLS
A. MAPPING	1. Integrated Atlas of Disability Services
B. CODING	2. Semi-automated tools for service coding (DESDE-AND)
C. MONITORING	3. Report Card Indicators
D. REPRESENTATION	4. GIS Spatial Analysis Tools
E. CONNECTIONS	5. Functional Network Analysis (FNA)
F. SIMULATION	6. Modelling in decision support systems

What is the importance of service mapping for planning and organizational change?

Maurice Bisognano [4] has enumerated four essential questions for organizational change and leadership, based on W. Edwards Deming principles on the quality of care (Box 2). These questions are also critical to understanding the importance of service mapping from a systems perspective.

Box 2. Four basic questions for service improvement and leadership

- Do you know how good you are?
- Do you know where you stand relative to the best?
- Do you know where the variation exists?
- Do you know the rate of improvement over time?

It is possible to re-phrase the leadership questions outlined in Box 2 as follows:

- Does the jurisdiction (Country, Region, Local district) have the right number of services and places (e.g., hospital, supported accommodation beds) for people with a disability?
- Are they in the right places?
- Does the region have the right mix of services, for example between health care, social services and support services or between hospital and community care for people with a disability?
- Does the region have the right mix of staff across these services?
- What is the impact of the strategy/intervention in the overall efficiency of the system?

- Using simulation modelling, what is the relationship and impact of the changes in disability specific services with other key elements of support services, such as health care, social services, housing, employment etc?
- How do results from models compare with official plans or goals? How do modelled results compare with reality?

Effective models of planning and decision-making can drive better service performance, through [5]:

- Reduced uncertainty by increasing information on the health system
- Clearer identification of the key determinants factors of efficiency within a system
- Clearer description of complex service performance for benchmark analysis
- Greater system understanding
- Improved resources allocation and management

Hence, the importance of, and opportunities service mapping provides for decision-makers, and in turn end users, are significant.

Box 4. Characteristics of Effective Planning which can be enabled by service mapping

- ❖ The capacity to provide bottom-up information on service availability and capacity at a local level
- ❖ The facilitation of gap analysis (where are services missing?)
- ❖ Disambiguation and standard coding of services
- ❖ Enabling examination of comparative efficiency of service systems
- ❖ Linking this work to an explicit theoretical framework and evidence base
- ❖ Linking mapping to other 'service maps' and drive better evidence-informed decision-making (e.g. housing, financing)

As a tool, the use of 'ground up' information combined with population information is increasingly being used to understand population patterns and environmental features [6]. Potentially, service maps could assist service users, service providers, all levels of government planners and funders of services depending upon the data availability and quality, the data systems to feed the mapping tools, and the understanding and knowledge of the user. For example, for a service user various forms of maps or visualisations can tell them where a service is, or what is available elsewhere. For a provider, these tools can reveal where a gap exists in the community and relate the care gap to needs which they may then organise to meet. From a government perspective, mapping can help with resource planning and highlight areas of need or inequity.

Mapping can enable the identification of geographical areas or particular groups who are being under served, enabling governments to make decisions about where and how to 'step in' to service systems or facilitate markets to adjust, inject resources or even directly take responsibility for a service need.

A note on 'person- centred' perspective service maps

A potential integrated 'people perspective' disability service map could provide bottom-up and top-down information of the whole system of all relevant human services in a region (both disability specific e.g., supported accommodation services and mainstream services e.g. hydrotherapy).

At the macro and meso level information for use by government and industry policy and market planners; meso and micro information for service providers to use in business and planning service delivery; and finally, for empowering and resourcing people with a disability to enable sourcing and choosing their service provider. A people/person perspective service map must provide 'what is' rather than relying on directories and advertised or promoted services (e.g. service organisation websites). Theoretical market information or plans of what services 'should be' are of limited use to stakeholders in the sector. Only when the reality of what services there are, the information on context, social and demographic characteristics of the area, capacity and their characteristics are known (including critically in the disability service market - organisational stability and inclusiveness) can benchmarking occur, gaps identified and then the information used in co-design planning approaches for market change and development.

Crucially, without some form of mapping in place governments cannot be certain what services are being delivered where and to whom, and problems cannot be addressed, nor improvements made. At its core, service mapping supports effective decision-making for system planning.

3. Six tools for service mapping

Before providing a detailed overview of six tools that can comprise a service mapping toolkit, we first outline the tools briefly here. The summary table below describes the extent to which the identified mapping tools in Australia can currently answer they key elements or questions.

- What services are needed?
- What services are available?
- Where do services exist?
- What is the usage of services?
- Are services inclusive?
- Are services effective at achieving outcomes?

The six tools are:

1. Integrated Atlas of Disability Services
2. Semi-automated tools for service coding (DESDE-AND)
3. Report Card Indicators
4. GIS Spatial Analysis Tools
5. Functional Network Analysis (FNA)
6. Modelling in Decision Support Systems

The evolution of these tools and the extent to which they have been tested, evaluated, validated and deployed worldwide is provided. While this evolution is ongoing, current choices are limited – particularly for tools that properly describe the full context of systems of health, social and support services or human service delivery.

The summary Table (see Table 2) demonstrates the potential of service mapping to address these issues, but also the considerable work to be done before this potential can be realised.

Table 2. Towards a Decision Support Toolkit for disability planning that incorporates service mapping

Element	TOOLS					
	Integrated Atlas [Salvador-Carulla et al. 2013]	**DESDE-AND [Lopez-Alberca et al 2020]**	**Report Card Indicators [Furst, Gandre et al. 2019; Bagheri et al 2019]**	**GIS Spatial Analysis Tools GIS**	**Functional Network Analysis Tool [Carey et al. 2020]**	**Modelling [Chung et al 2018), Garcia Alonso (2019)]**
What services are needed?	No. However, it provides basic information for needs assessment (NA). NA requires information on a) population characteristics b) on service provision c) resource, and d) demand. The Atlas provides the info on b)	No.	Partial *It provides basic information for needs assessment*	No. However, it is an essential visualisation tool to inform planning and in the identification of patterns of care. It has been used to adjust service planning to social and demographic indicators at area level	Partial. *By working to highlight thin markets the FNA tool can give an indication of potential service categories that are needed.*	No.
What services are available? ***Service provision:*** ***Availability*** ***Capacity*** ***Workforce***	Yes. It uses an international system (DESDE-LTC) to assess availability and capacity. The system has been used for mapping disability services in Spain, social services in Spain and Australia (e.g., Housing and Homeless services), and Psychosocial Services in NSW (Western Sydney PHN).	Yes. This is a semi-automated tool for routine mapping and updating disability services in Andalucia (Spain). It produces service directories and allows development of dashboards of service availability, capacity and geolocation	No. But composite indicators of social and demographics, service availability, capacity and workforce can be developed to monitor the system	Partial. It is used in combination with the DESDE mapping tool	Partial. It uses NDIS utilisation data to visualise available services, but it is not a system for identifying available services that are under-utilised.	Yes It identifies typologies of services in Modelling can simulate changes in availability of care (services and workforce) in catchment areas

Element	TOOLS					
	Integrated Atlas [Salvador-Carulla et al. 2013]	**DESDE-AND [Lopez-Alberca et al 2020]**	**Report Card Indicators [Furst, Gandre et al. 2019; Bagheri et al 2019]**	**GIS Spatial Analysis Tools GIS**	**Functional Network Analysis Tool [Carey et al. 2020]**	**Modelling [Chung et al 2018), Garcia Alonso (2019)]**
Where do these services exist?	Yes It uses GIS to geolocate the services by their codes	Yes	No	Yes We have developed special analytics (e.g., heat maps) to monitor key indicators, availability, capacity and workforce.	No, currently FNA does not visualise according to GIS.	No However, this information can be incorporated into scenarios and models of care
What is the usage of these services? ***Resource use***	Yes Atlases that incorporate service utilisation data have been used in Europe	No, but the information of provision and usage can be combined in an aggregate dataset	Yes It is critical to summarise and represent service utilisation in a standard way. Report cards play a critical role with this.	No	Yes. Using NDIS payments data the tool visualises usage of services.	Yes. It can incorporate data on service utilisation and provide information on the better ranges in one specific services (e.g., FTE of staff in a residential setting) or in catchment areas (e.g., optimal rates of beds in community residential services)

Element	TOOLS					
	Integrated Atlas [Salvador-Carulla et al. 2013]	**DESDE-AND [Lopez-Alberca et al 2020]**	**Report Card Indicators [Furst, Gandre et al. 2019; Bagheri et al 2019]**	**GIS Spatial Analysis Tools GIS**	**Functional Network Analysis Tool [Carey et al. 2020]**	**Modelling [Chung et al 2018), Garcia Alonso (2019)]**
Are the services inclusive?	Yes – the system is prepared to incorporate and geolocate patterns of inclusiveness if the data is available.	No	Partial. Available information can be combined to produce synthetic indicators of inclusiveness of catchment areas. A similar approach has been used to develop a composite indicator of social fragmentation (Bagheri et al 2019)	No	Partial. Currently does not visualise inclusivity however inclusivity factors are easily integrated through a filter the 'live' app if inclusivity data is made available.	Yes. It can use data from composite indicators to develop and test models of inclusion
Are services effective at achieving outcomes? ***Effectiveness*** ***Efficiency*** ***Stability*** ***Entropy***	Yes – a spatial analysis of relative technical efficiency has been incorporated into atlases in Europe	No	Partial. the information provided by report card indicators is essential to inform efficiency analysis	No	No.	Yes The analysis of effectiveness and efficiency is better analysed using modelling (for example RTE analysis)

(1) GIS Techniques and models used in VIDEA: a) Moran's I and the Getis-Ord's Gi global Indexes (Maas et al 2019; Bagheri et al, 2019); b - Multi-Objective Evolutionary Algorithm (MOEA) Salinas et al, 2012

(2) Visualisation tools used in EbCa - a) Visualisation of complex pattern of healthcare of catchment areas using GHSOM; b) parallel coordinates

Tool 1: Integrated Atlas of Disability Services

I. Purpose

A cartographic atlas is a collection of maps describing the overall geography of a territory and/or focusing on specific aspects, such as health and health care, social and support services. There are several previous examples of mental health atlases. The World Health Organization (WHO) has published five mental health atlases, which constitute the most continuous collection of health atlases. These atlases use the WHO-AIMS (Assessment Instrument for Mental Health Systems) tool to collect national indicators, but cartography is practically absent. In Australia, the Atlases of Variations in Medical Practice series do not provide information on disabilities. To improve upon these approaches, the "Integrated Atlas of Care" provides a description and representation of the whole system from a bottom-up perspective, using an international coding system called "Description and Evaluation of Services and DirectoriEs" (DESDE).

II. Data utilised

The analysis of context includes geographic, demographic and socioeconomic factors, the provision and use of services, legislation and costs. It provides information on the service availability using a standard classification for coding services. To promote commensurability, the DESDE system uses a novel unit of analysis of services called "Basic Stable Inputs of Care" (BSIC). BSICs are defined as stable teams of professionals dedicated to serving a specific population group on a regular basis. Stability is both temporal (at least 3 years old) and organizational (has its own facility, the same team of professionals, administrative or accounting support and an independent budget). These BSICs are described using a "Main Type of Care" (MTC). This is a taxonomy comprising over 110 codes. To overcome the problem of terminological variability, this system uses an international glossary defined by the main activity of the service instead of its name. These MTC follow a taxonomic tree with branches corresponding to six major areas of care: residential, day, outpatient, accessibility, information and evaluation, and self-help. These branches are successively subdivided according to attributes such as crisis care (acute), mobility, intensity and the professionals required for the care provided by the service.

III. Data source considerations

The creation of an atlas consists of 5 fundamental steps (Figure 1).

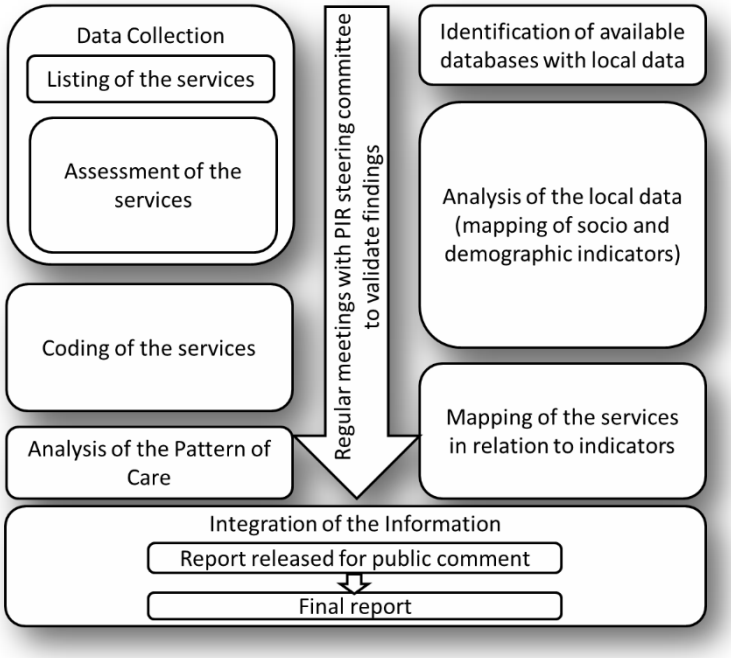


Figure 1. Procedure for the development of an integrated mental health atlas.

First, the territorial units are identified, and digital cartography is generated based on the selected zoning. The boundary of the study area is key to identifying subsystems and nested systems, assigning values and ratios to each indicator, and performing spatial analysis. Second, the relevant organizations in the delimited area are identified, and a list of services is created by applying inclusion and exclusion criteria agreed upon with public agencies. Information is collected through a personal interview with key local agents or service managers or through an online questionnaire. Third, sociodemographic information is collected from official secondary sources according to the previously determined zoning.

IV. Information the tool provides

The Atlas provide comprehensive information on the whole system including boundaries and jurisdictions, census data, determinants of care, system of care provision (availability, capacity and workforce). This information includes:

a) The local health care ecosystem from a broad context of care (whole system including the relevant social and demographic factors.
b) The service delivery system including availability, capacity and workforce. It includes services in all relevant sectors designed from a local perspective, and from the bottom up, an approach that analyses the provision of services in a comprehensive manner and incorporates experts in code-signing and analysis.

c) The geolocation of the services identified

V. Primary uses of the tool (relevant to decision making)

This system permits a codified, systematic response to key questions necessary for effective service planning. It has been used for gap analysis and for exploring the balance of care. It also allows comparison of the patterns of care with other jurisdictions, other target groups or across sectors.

VI. Enhanced potential of the tool with additional information

The comparison with another jurisdiction facilitates gap and benchmark analysis. The combination of information on availability with prevalence and incidence allows the analysis of population-based unmet needs, while the combined analysis with qualitative and quantitative information using needs assessment instruments could be used to estimate individual unmet needs. Consecutive surveys of the service delivery system over time permits the analysis of the evolution of services in relation to policy, societal, financing or environmental changes.

VII. Limitations

The Atlases are limited by data availability and quality on services and other domains (physical, geographical, social and demographic indicators). The collection of bottom-up information using the DESDE Tool is time consuming and requires training for using an international coding system. Due to changes and variation of services, the information should be gathered on an annual basis to be used in planning. IT systems like interactive mapping, real time dashboards and other should be implemented in combination with the Atlas. The Atlases do not assist with determining demand/what services are needed. This requires assessment data on the needs of individuals not currently available. Whilst there is potential with the limited needs data from NDIS participant service plans (recognising this represents approximately 11% of people with a disability) there is the challenge of NDIS service codes do not correspond to the DESDE service mapping, nor do they represent all services needed rather those only funded by NDIS.

VIII. Case study

The Global Atlas Project: Integrated Atlas of Care in Local Districts

DESDE-LTC has been used to map mental health and psychosocial services in 13 Primary Health Networks in Australia comprising over 45% of the total Australian population (https://rsph.anu.edu.au/research/projects/atlas-mental-health-care). Our recent analysis of the mental health service planning landscape suggested regions had responded to the demand of service mapping by partially using one system or another, choosing not to develop any systemic planning infrastructure at all, or even, in some cases, building their own bespoke

system. None of these outcomes make for a robust, systemic planning process – in mental health, health or across the broader disability sector.

A recent systematic review indicates that DESDE and related systems have been used, in 71 studies conducted in 34 countries [7, 8].

Who receives services?

The DESDE coding system is part of a multiaxial coding for mapping services. The target population is coded first, and it provides a highly granular description of the recipient of the service according to age, gender, risk or vulnerable group, ICD coding and ICF coding. This has been developed using a semantic interoperability approach that links the coding to the WHO-FIC and other international coding systems.

What services?

The coding system uses a validated system for the standard description of the microsystem of care (BSICs) (Care teams) and the DESDE taxonomy of 'Main Types of Care' (see explanation of the DESDE coding system in Table 2). Directories and Atlases of disability and social services have been produced and used for disability and social care planning in Spain. Psychosocial services including care for homeless persons, and services for long term care have been mapped also in Australia. The longitudinal impact of NDIS in the provision of psychosocial services has been analysed in Western Sydney [9] and in Canberra [10][11].

From whom?

The Atlases incorporate a detailed description of the staff of every BSIC or care team and aggregates them to several levels of the organizational ecosystem (micro, meso and macro). This provides a unique capacity of relating workforce capacity to units of care.

At what cost?

The DESDE system has been used extensively for estimating units of cost analysis and context of health economics studies [8]. The European Commission project PECUNIA is currently using this approach to design standard units of costs analysis that will facilitate comparison and aggregation of the results of health economic studies in different jurisdictions and countries

With what effects?

The DESDE coding and its mapping has been used for modelling technical relative efficiency and evidence informed policy. The modelling of efficiency is currently used in the Basque Country and Catalonia (Spain) and England. A proof-of-concept study is under progress in ACT.

The Atlas of Mental Health of the Australian Capital Territory (ACT) PHN (Primary Health Network) region of 2016 provided a picture of the mental healthcare ecosystem of ACT in the context of its social and demographic context and its policy context, identifying areas of strength and gaps in service provision.

The findings in the ACT included the identification of specific gaps in the region and alternatives to acute hospitalisation. The gaps included availability of whole day support services such as day centres providing opportunities to make social connections or to develop skills. There was a complete absence of work or employment related services.

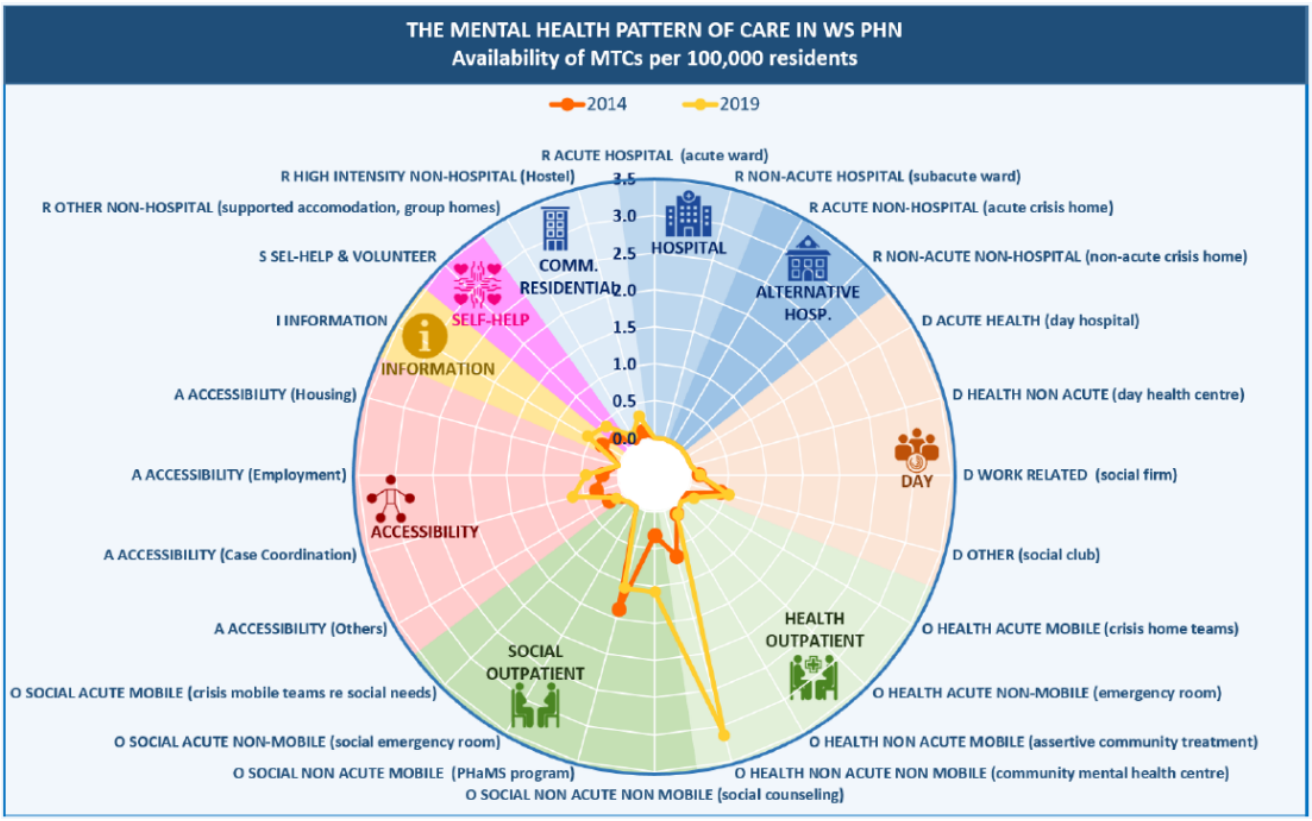
On the other hand, when compared to other regions in Australia, ACT's pattern of service provision was more community care oriented, with a higher availability of community residential care and a relatively high rate of services provided by the non-government sector. There were also more services for specialized demographics such as the LGBTIQ population, although services for Culturally and linguistically Diverse (CALD) populations, were absent. Overall, service provision in the ACT provided a more complex pattern of care than in other Australian regions, illustrated by its higher rate of services assisting people to navigate the system e.g., case management.

The pattern of care identified in the ACT was broadly like that found in other regions in Australia similarly mapped: the gaps in day services and in alternatives to hospitalisation being a common characteristic of the Australian regions. However, while the level of community based care in ACT was greater than that found in other Australian regional Atlases, it was lower than most international regions mapped in the same way, indicating a slower transition to community based care in Australia than in other countries, including countries such as Spain and Chile with a lower GDP.

In the on-going mapping of MH services in ACT we have identified a major change in the financing and payment system in psychosocial services after the implementation of NDIS. The changes in the psychosocial system may indicate a different level of elasticity of the social sector when compared to the health sector and require further analysis. The two are quasi-markets but with completely different levels of elasticity which may explain the differences in the health service subsystem for "severe/chronic/complex" conditions and the service subsystem for "disabilities".

In Western Sydney, the Integrated Atlases of Mental Health Care of 2015 and Integrated Atlas of Psychosocial Services of 2019 provide insights into the evolution of a mental health ecosystem during a period of significant change (before and after NDIS) (see Figure 2 below). The main findings were an almost threefold increase in the availability of psychosocial services, and a trend towards more traditional health related services rather than social care.

Figure 2 Comparison of Pattern of Psychosocial Care Provision in Western Sydney before and after the implementation of NDIS (2014-2019)



However, Atlas data indicated that this increase in services was in number rather than type of service, and the system overall had evolved to become more complex, with an increase in satellite services more typical of rural areas, and in the number of services lacking funding stability (see Figure 3 below). The increase in overall availability appeared to be partly attributable to the increased presence of larger national organisations in the region, with new providers moving in and current providers increasing their service provision. As in the ACT and other Australian regions, gaps were identified in day-care, particularly health related day care (day hospitals and rehabilitation services), and in community residential care.

Additionally, some priority areas identified as priority areas by the PHN, such as the LGBTIQ population, older people and people experiencing homelessness in addition to mental illness, were found to be lacking.

Figure 3 Evolution of number and types of Psychosocial services in Western Sydney before and after the implementation of NDIS (2014-2019)

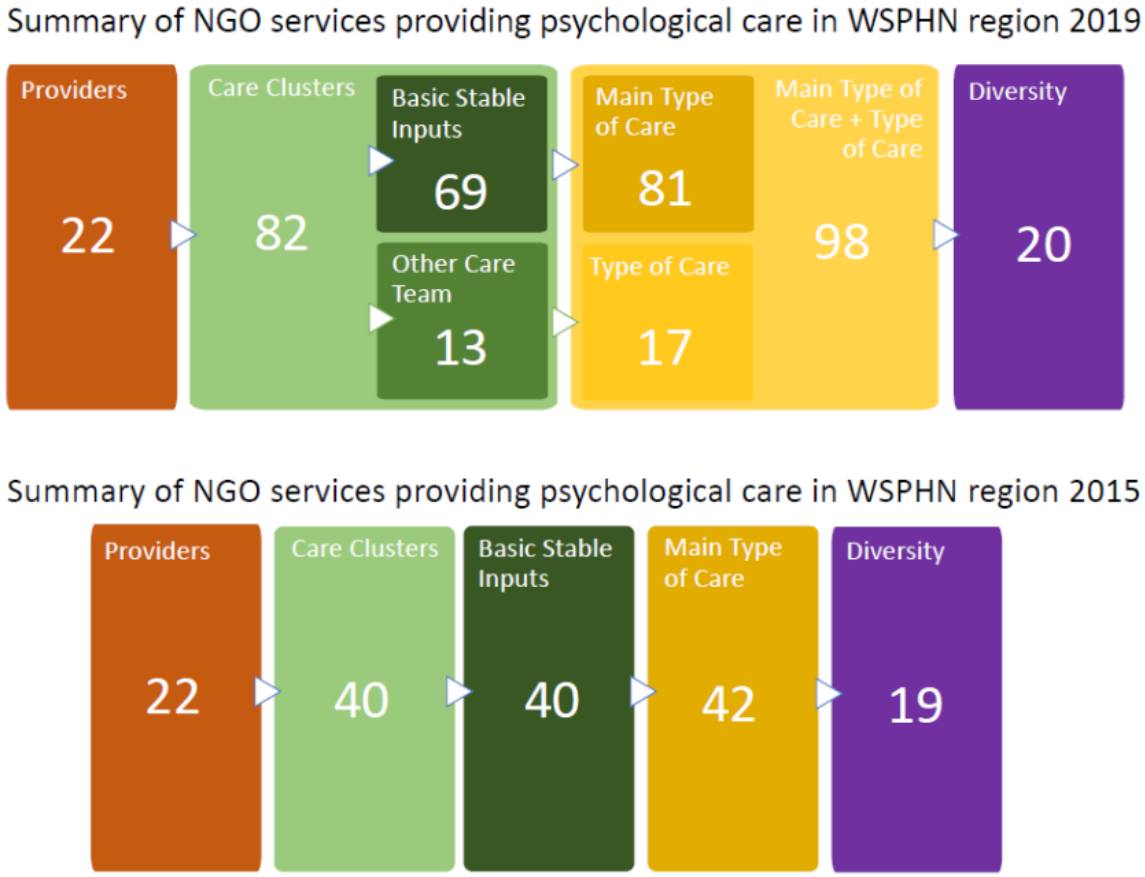


Figure 3 indicates an increase in the overall availability of psychosocial services in Western Sydney, and the complexity of the provision system, while the number of providers and the diversity of the care supply offer remains the same.

CASE EXAMPLE: Integrated Atlas of Psychosocial Care in Western Sydney PHN

(Evolution of the Psychosocial Care system before and after NDIS)

The ATLAS findings DO NOT support two main assumptions underlying the design of the NDIS as a competitive market:

1) A competitive market of disability services will lead to a system with a lower number of larger providers that could scale up and make the care supply more efficient

- *The number of providers has not changed*

2) The development of a competitive market in disabilities will enhance a more diverse offer of services.

- *The same number of providers has increased the number of services providing similar activities. The diversity of the supply offer has not increased.*

This case study also provides key answers to the questions from the NDDS scoping

What problem/need does it address?

Atlases have the capacity to identify gaps in the service provision system and to determine technical efficiency of the whole system if service use data is available. Service utilisation adds another layer of detail that is interfaced with the other information e.g., social determinants and geography. Apart from their descriptive role, Atlases can also provide key information to evaluate the quality-of-care provision and eventually explain causal relations within the system. Figure 3 has shown how the two main assumptions of the NDIS as a market system have not been identified in Western Sydney. Paradoxically these assumptions were made without enacting any evaluation system to monitor the evolution of the disability system before and after NDIS.

What data does it require?

The Atlases require at a minimum detailed information on services obtained from service mapping plus relevant geographical, social and demographic indicators. The more information available, the more granular and useful the Atlas. The Atlases can utilise data from the domains of physical, geographical, health, social, and determinants of health (social and demographic indicators e.g., housing, disability support pension) and where available service usage (e.g., NDIS service claims, billings through Medicare codes).

Location and Geography

Atlases can use GIS to geolocate services by their codes, can create dashboards of service availability and capacity (e.g., staffing). (note this does not refer to service usage, access issues or delays in services e.g., waiting lists).

Inclusiveness

Inclusiveness concerns cultural and socio-economic diversity, gender, people with a disability and others. Inclusivity can be bi-directional not only mainstream including minority groups e.g., intentional community residential services where there is a target of diversity of resident needs. The Atlases has the capacity to incorporate patterns of inclusiveness if relevant social and demographic data is available.

Applicability

Apart from their extensive use in mental health, Atlases have been applied to describe and code disability services. DESDE has been used to code the whole national provision system of services for disabilities in Spain, to compare psychosocial services across districts and countries with very different patterns of care (e.g. Madrid in Spain and Sofia in Bulgaria) [12], and to analysis patterns of homeless care in Melbourne, among many other uses.

They permit the organisation and coordination of regional information for greater understanding of service availability, using a consistent taxonomy. Apples are apples. The Atlas can also join ‘disability’ services with other services used by people with a disability, building a more holistic bigger picture of the service landscape.

Tool 2*:* DESDE-AND

I. Purpose

The DESDE-AND is a companion tool to DESDE that can semi-automate the collection of service information, that can be used as a core module of decision support systems to guide planning in complex cross sectoral areas such as combined social and health care. It provides automated codes of services using the Description and Evaluation of Services and DirectoriEs for Long-Term Care (DESDE-LTC) system.

II. Data utilised

The existing directories of care in a given area are used to identify all the available services providing care for the same target population in this area, regardless of the sector of origin, the funding source or the main agency. Once the services have been identified, a survey is conducted with the service managers using a semi-automated tool that gathers information on the activity and the characteristics of the existing services to code them using the DESDE-LTC. This system provides information on service availability, place capacity and workforce.

III. Data source considerations

The data sources are the same that are used in the DESDE surveys for producing the Atlas of Integrated Care.

IV. Information the tool provides

This system provides automated information on service availability, place capacity and workforce.

V. Primary uses of the tool (relevant to decision making)

The automated version of DESDE-LTC (DESDE-AND) provides basic information to:

1. Identify care provision and care gaps
2. Provide international comparison
3. Provide basic information for benchmark analysis and relative technical efficiency analysis
4. Inform case managers for producing case plans
5. Inform navigation systems for consumers, carers, clinicians, case managers and planners.

VI. Enhanced potential of the tool with additional information

Similarly, to the information provided by DESDE, the automated coding information could be completed with other types of information on resource utilisation, patient reported outcomes and consumer satisfaction, needs assessment, costs, and complex indicators.

By combining these different types of information and analytical tools we can produce an advanced decision support systems for evidence-informed policy and planning.

Limitations

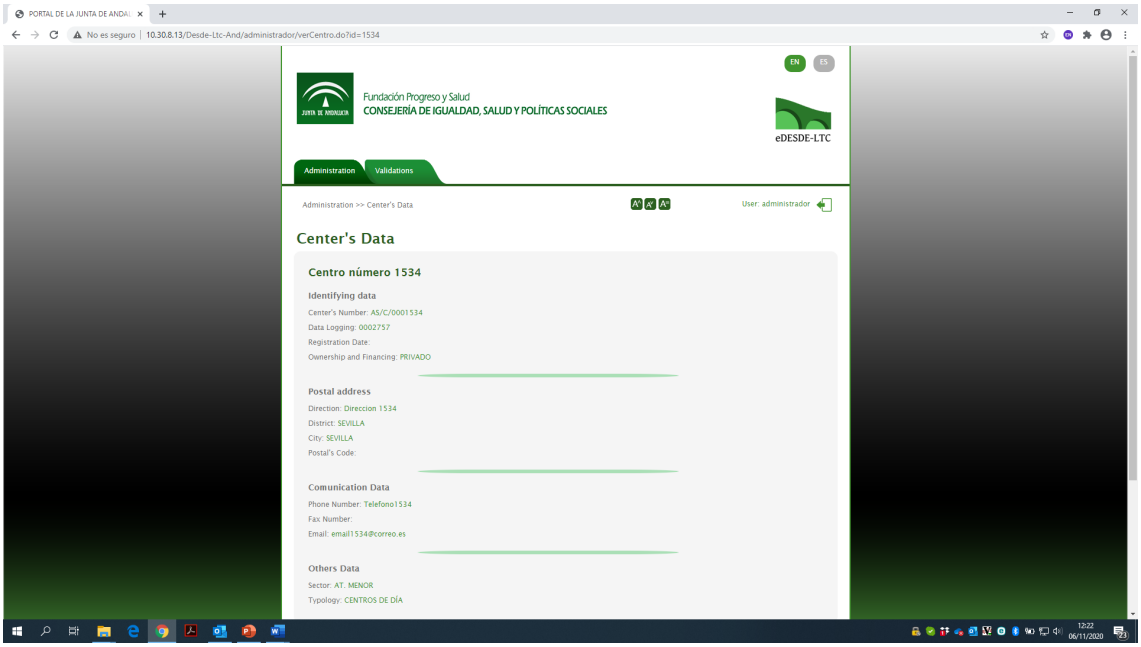
The automated system (DESDE-AND) replaces the previous method based on individual interviews with the managers conducted by a trained coder. The mapping of areas using the paper and pencil version (DESDE-LTC) requires direct contact with all the managers of the existing services, conducting personal interviews, are time-intensive and require significant training. The automated system is only available for mapping social care (including services for disabilities) in one region in Spain (Andalucia). Although DESDE-LTC is available for international use, its automated system (DESDE-AND) has only been tested in one region, and it will require a new version to be applied in Australia.

IX. Case study: DESDE-AND in Andalusia

DESDE-AND has completed the maturity phase and the piloting and it is ready for implementation in the dataset of social services in Andalusia. Figure 4 shows the DESDE-AND webpage in the regional minister of social services with the data available on a) General data on every service, b) DESDE coding, c) Geolocation of services by types, and their characteristics. Next step involves linking the automated system for coding service delivery with the electronic social record and other datasets (semantic interoperability) [13], and the development of a navigation system for consumers and planners.

Figure 4. The Automated coding of Social Services in Andalucia (Spain) using DESDE-AND. It includes geolocation of services and a display of the main characteristics of the services: a) General data on every service, b) DESDE coding, c) Geolocation of services by types and characteristics.

a.



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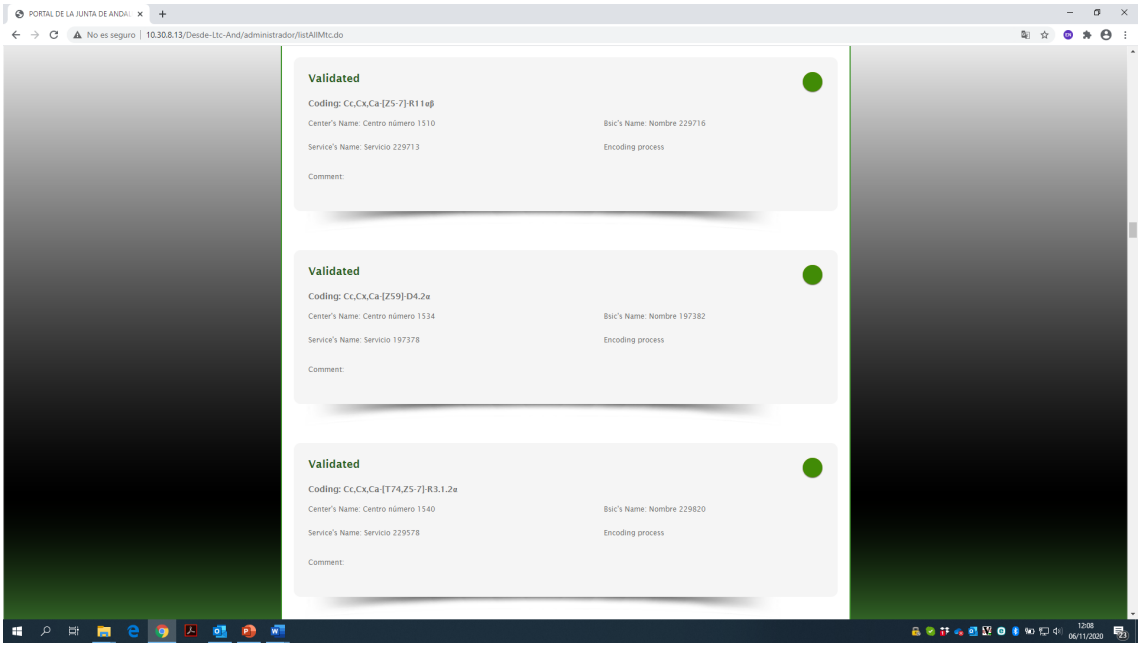

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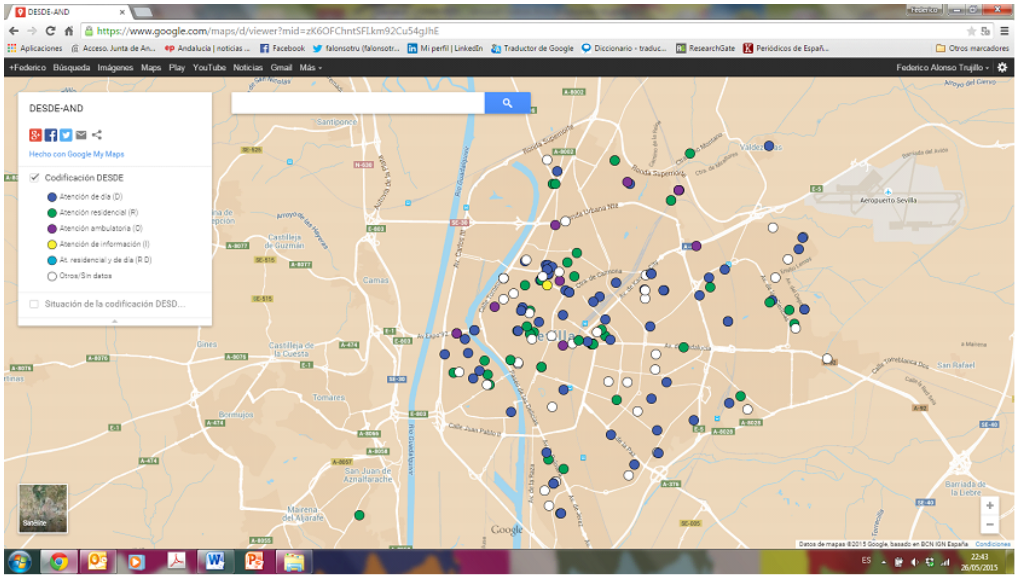
DESDE-AND
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DESDE-AND
Hecho con Google My Maps
Codificación DESDE
Atención de día (D)
Atención residencial (R)
Atención ambulatoria (O)
Atención de información (I)
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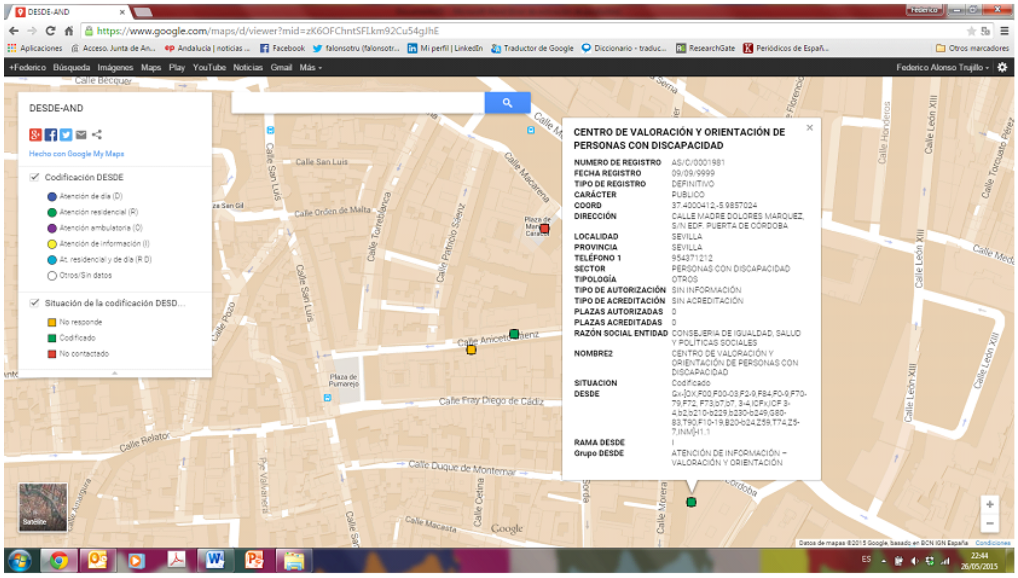
DESDE-AND
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Atención residencial (R)
Atención ambulatoria (O)
Atención de información (I)
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Otros/Sin datos
Situación de la codificación DESD...
No responde
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FECHA REGISTRO 09/09/9999
TIPO DE REGISTRO DEFINITIVO
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DIRECCIÓN CALLE MADRE DOLORES MARQUEZ, S/N EDF. PUERTA DE CORDOBA
LOCALIDAD SEVILLA
PROVINCIA SEVILLA
TELÉFONO 1 954371212
SECTOR PERSONAS CON DISCAPACIDAD
TIPOLOGÍA OTROS
TIPO DE AUTORIZACIÓN SIN INFORMACIÓN
TIPO DE ACREDITACIÓN SIN ACREDITACIÓN
PLAZAS AUTORIZADAS 0
PLAZAS ACREDITADAS 0
RAZÓN SOCIAL ENTIDAD CONSEJERIA DE IGUALDAD, SALUD Y POLITICAS SOCIALES
NOMBRE2 CENTRO DE VALORACIÓN Y ORIENTACIÓN DE PERSONAS CON DISCAPACIDAD
SITUACION DESDE Codificado
RAMA DESDE I
Grupo DESDE ATENCIÓN DE INFORMACIÓN – VALORACIÓN Y ORIENTACIÓN
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Tool 3: Report Card Indicator

I. Purpose

Indicators are key tools for ensuring that the functioning of care systems can be comprehensively measured for monitoring and evaluation. Fundamentally indicators should aim to have some key characteristics, namely: i) be identified according to a defined objective/purpose, ii) be operationally defined for standardised uniform measurability; iii) include a description of their metric properties, iv) be feasible to collect data in a specific context; and v) analysis should result in practical recommendations upon which health and social care may be improved. In addition indicators should be arranged into comprehensive sets that vary according to the purpose of the indicator set, the geographical level of analysis (e.g. national, state, district), and their use in different environments (e.g. rural versus urban) [14, 15].

The identification of meaningful indicator sets for disability services could benefit from transfers of the experience in other sectors. A decade ago WHO made a call for action to "develop ongoing systems for regular and sustainable collection and analysis of disaggregated data"; "tools and processes designed to empower communities in local decision making and tackle urban health inequities", and the development of "technical assistance and support capacity-building among Member States and local governments with the aim of improving urban health and reducing urban health inequities and the negative impacts on health of urban policies and programmes" [16].

Data utilised

All relevant sources of data can be considered, aligned with the systems and indications released by the National Disability Data Asset. Synthetic indicators validated for specific target groups and settings are a relevant component of report cards. The case study presents two examples of composite indicators and the data they use.

II. Data source considerations

Main data considerations in the development and use of report cards are discussed in the limitations section.

III. Information the tool provides

The information provided on the care provision system requires multiple sources including information on the social and demographic characteristics of the population, their lifestyle and other determinants of health, the service delivery, the resource utilisation in the same area, and information on outcomes. Therefore, report card indicators should combine information on provision, utilisation and outcomes. These provide the basic information for contextual analyses and understanding the process in health care ecosystem. To be workable and easily represented, indicators should be merged into synthetic or composite indicators.

IV. Primary uses of the tool (relevant to decision making)

The indicator report cards help policy makers to quantify context and design interventions health management.

V. Enhanced potential of the tool with additional information

Information from report cards could be transferred to Atlases of Integrated Care that provide graphical representation of the comprehensive set of information on socioeconomic indicators, service provision and utilization to facilitate comparisons across jurisdictions and monitoring of the evolution of the care system. In the Integrated Atlas of Mental Health Care information on social and demographic information has been developed from the ten indicators of the European Socio-Demographic Schedule (ESDS). The indicators are presented in thematic maps according to their spatial reference unit (e.g., coverage areas of community rehabilitation centres) and in radial charts allow comparisons of the situation of each unit of analysis

VI. Limitations

Determining useful list of health indicators is difficult for a variety of reasons. First, the social and health care ecosystem is a multi-level structure including nano (biological and biomarkers), micro (consumers), meso (local level providers), macro (state level organizations), and mega level (country or national level). A problem of combining different data sources in a single report card is the different catchment areas of reference considered in the original sources and datasets. Some of them provide indicators at SA1 while other use SA3 or even State or national aggregated data. This problem is augmented by the different boundaries of social and health care for the same population group. Second, in this ecosystem health, social, educational and criminal and justice services coexist, and the care teams are multidisciplinary in which an integral care focus should be adopted [3]. Third, there are few reliable “hard” indicators of functioning and many of the impairments, limitations of abilities and restrictions of participation assessed or the results, particularly in psychosocial disabilities, which complicates epidemiological and outcome research. Fourth, the dates of data collection of different indicator data set vary hugely. As an example, the more recent surveys on prevalence and incidence of mental disorders in Australia are 20 years old, and census data are collected has been included late into the general health system (in Spain from 1986), it presents problems of under-financing and the lack of national data bases which exists in other disciplines (e.g., Oncology or AIDS).

I. Case study: Development of Composite Indicators for monitoring Social Fragmentation.

Protective social processes within communities or neighbourhoods, such as social capital, social cohesion and collective efficacy, are important contextual influences on population health, particularly in disabilities.

Such protective processes are more common in areas that are less socially fragmented, such as those with less residential mobility, low levels of non-family households and with more adults in marital or other partnerships.

In fragmented areas, by contrast, resident interactions tend to be fewer and of lower quality; aspects of social capital, including trust, social norms and reciprocity, are harder to maintain and more people are socially isolated. Fragmentation of social environments is of ongoing interest to health and social science researchers for its potential relationship with a range of health outcomes including mental ill health. 'Social fragmentation' is a term defined as a lack of opportunity for social integration and inclusion originating in Emile Durkheim's early research. Durkheim high-lighted that a community which is highly fragmented would be less able to provide 'healthy' levels of support.

Our group at ANU has developed a social fragmentation index (SFI) to explore variation in rates of chronic conditions in Australia (depression, diabetes, dementia)[17, 18]. We measured area-level social fragmentation at the Statistical Area level 1 (SA1) using information from the 2011 Australian census. SA1s typically have a population between 200 and 800 persons (average population approximately 400 persons), which allows the separation of areas with different geographic characteristics within suburb and locality boundaries across Australia.

Candidate variables (indicators) for the proposed SFI that were available at this geographical resolution included the proportion of: population mobility < 1 year (people living less than a year in the neighbourhood), privately rented households, single-person households, nonfamily households, unmarried persons, households with school-aged children, recent immigrants < 1 year, immigrants arrived > 15 years ago, residents living > 5 years in the neighbourhood, and people who report volunteering. Due to the variability of the contextual factors across local communities, composite/synthetic indices should be adapted and adjusted to the local context and one single indicator of the composite index relevant in one area may not be relevant in another area. The Australian neighbourhood social fragmentation index captures three domains: attachment to the neighbourhood, sharing values and norms and transience. We selected available variables from the Australian Bureau of Statistics that covered each of these domains. Our index included more candidate subdomains and indicators compared to the UK and NZ indices, to ensure sufficient coverage of relevant metrics of social fragmentation [15-17]. We conducted principal components analysis (PCA) to explore relationships between these area-level characteristics and to select the most parsimonious set of variables. Data from across Australia representing 53,137 SA1s and a population of 21,004,542 (after excluding outliers reflecting very low population SA1s) were included in the PCA. Scores based on the principal components were then used to create a composite (synthetic) index of social fragmentation within each SA1 area, labelled the ANSFI score.

Tool 4: GIS spatial Analysis Tools

I. Purpose

Geographic information systems (GIS) are computer programmes that combine spatial representation on maps with the exploitation and processing of georeferenced information. They rely on digital cartography with different territorial administrative and statistical scales. In addition, geographic information systems embed different spatial analysis tools to analyse and to model the spatial information to support decision-making and territorial planning.

II. Data utilised

Any geo-referenced data can be used in a GIS. This location y geographical coordinates allows us to display data on a map, as well as to analyse them by using spatial analysis tools. GIS rely on digital cartography with different territorial administrative and statistical scales. Nowadays it is available cartography from any area around the world in a proper format to be used in a GIS. However, in most cases, this cartography needs to be edited to adjust for the zoning levels of health and social services, which do not always fit standard territorial divisions.

III. Data source considerations

Spatial data typically comes from secondaries sources, such as statistics agencies (local, regional, national or international), administrations and governmental departments (economy, infrastructure, health, etc.). However, it is possible to use primary sources as well by registering the location of the information. In addition, geographic information systems can analyse geographic accessibility through transit areas or transportation costs (e.g., and spatial concentrations (hotspots) of, for example, the administrative prevalence of treated depression in primary care.

IV. Information the tool provides

GIS mainly provide cartography on spatial data, including thematic maps, locations, routes, etc. Later GIS can analyse and to model this data through spatial analysis tools. There are several spatial analysis tools, including clustering analysis, to identify clusters of spatial units with similar data (high/low values); spatial regressions, to study the association between indicators on the territory; or accessibility analysis, to study the travel time or distance to relevant facilities from anywhere.

V. Primary uses of the tool (relevant to decision making)

GIS display geo-referenced data on maps, and therefore represent the information on service provision, automated coding and from report card indicators described above. GIS inform decision-makers and planners about the geographical distribution of any key indicator. Besides, advanced spatial analysis provides new information from the original data. Clustering analysis allows decision-makers to identify geographical areas where high or low values of a

specific indicator (e.g., prevalence, mortality, admissions, etc.) are clustered. Later it is possible to study the relationships of these clusters with other related indicators or risk factors, such as health, environmental and sociodemographic indicators, which may advise on what specific health programmes or service-planning actions would be needed. The accessibility analysis can identify areas with poor accessibility to services. This may recommend the creation of new services or the development of satellite services or e-health.

VI. Enhanced potential of the tool with additional information

GIS and spatial analysis tools allow us to integrate different data and methodologies. The essential point is that data, which could come from any primary or secondary source, is geo-referenced. To avoid ecological fallacy, the more and smaller spatial units, the more detailed and suitable results. When data are geographically referenced, they can be managed with geographic information systems and be displayed and analysed using spatial analytic methods. GIS is a very useful component in any decision support toolkit.

VII. Limitations

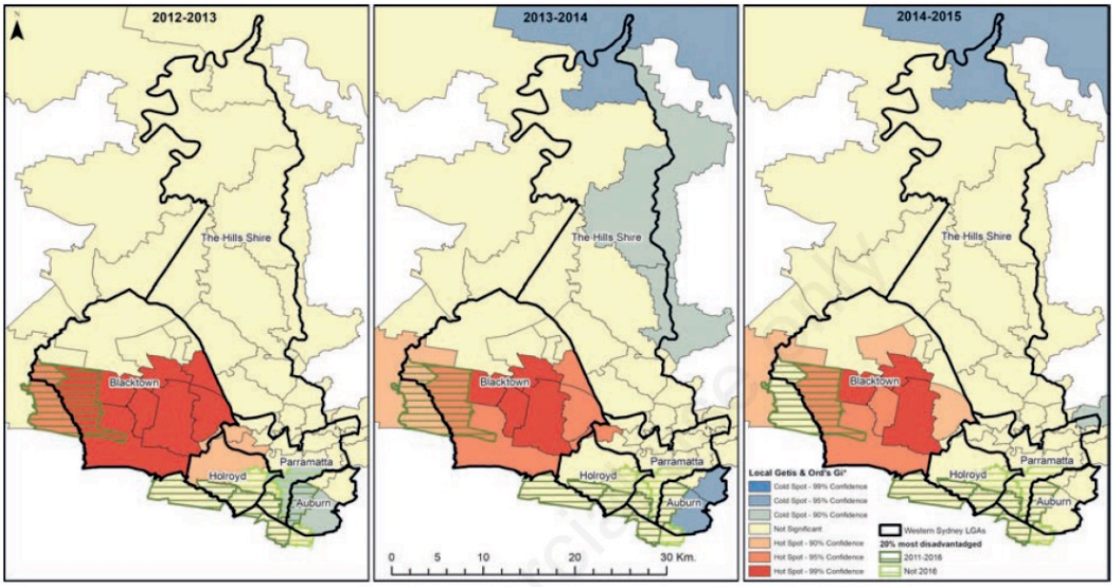
Despite the various advantages of utilizing data with geographical references, there are methodological caveats that researchers and planners should consider. The main limitation is the quality and availability of spatial data. The smallest spatial units available are required to avoid ecological fallacy problem, since conclusions for individuals living in a specific area cannot be directly inferred from the results obtained for the whole population group living in that area. Another common issue is the border problem, so the results of a clustering analysis would be biased in the borders of the study area when data from neighbouring areas are not considered in the analysis. In most cases, cartography needs to be edited to adjust for the zoning levels of health and social services, which do not always fit standard territorial divisions. Finally, there are very different methods of spatial analysis that provide different results. Analyses combining different methods are recommended [19, 20].

VIII. Case Example: Evolution of the provision of psychological care in disadvantaged areas in Western Sydney (Mass et al, 2019).

Access to Allied Psychological Services is a primary mental health programme targeting hard-to-reach populations throughout Australia. In our GIS study we identified patterns of referrals to the programme in the Western Sydney Primary Health Network region from 2012 to 2015. The referral rates were analysed by using spatial autocorrelation indexes and spatial regression. The study area was described through the identification of the most disadvantaged areas and through consideration of three socio-economic indicators: percentage of Aboriginal and Torres Strait Islander Australians, low educational attainment and low weekly incomes.

A large hot spot (identifying high referral rates) was located across the duration of the study in the south-western urban area that partially covered a disadvantaged area. The main cold spot (identifying low referral rates) was in the south-eastern urban area, covering another disadvantaged area, however critically this association disappeared over time. Our modelling showed that the referral rates had a direct association with the percentage of Aboriginal and Torres Strait Islander peoples with low incomes, and an indirect association with low educational attainment. An improvement of the accessibility and equity of service provision was identified over the four years of the study (Figure 5). The GIS technique is useful in monitoring and addressing inequality in health and social planning and policy.

Figure 5. Hot Spot analysis of the Analysis of the Allied Psychological Services referral rates by consumer postcode in Western Sydney Primary Health Network region (2012-2015). (LGA, Local Government Area).



Tool 5: Functional network analysis tool

This section presents a first case study demonstrating a new mapping tool developed for the NDIS - functional network analysis. This approach has been applied already in NSW to assist with the identification of 'thin' markets. We present its current strengths, limitations and potential.

Purpose

The problem or need that functional network analysis addresses is the challenge of identifying thin markets in the NDIS. Importantly, the functional network analysis provides an indication of where thin markets may be emerging, and which areas require further qualitative investigation to understand the specific thin market dynamics.

The purpose of functional network analysis is to understand the links between service provision and service users, and the strength of these links to determine which parts of the system need strengthening and improvement. The Functional Network Analysis Dashboard is currently in use by NSW DCJ to investigate thin markets in Walgett and Wentworth. A prototype of the dashboard based on mock data can be seen via this video walkthrough and some screenshots are included below.

Background

Functional network analysis is an approach to visualising and analysing market-based networks with the goal of identifying market gaps or failures (Reeders et al., 2019). This type of analysis can be used for any government-funded quasi-market and is currently being used for examining what is referred to generally in Australian disability policy as 'thin markets' in the NDIS. Functional network analysis results in a graph or map of different forms of market structure, which can be used to gain insight into and communicate about thin markets in the NDIS. Functional network analysis is the concept that underpins the maps of the disability service sector that UNSW have been producing via their online dashboard.

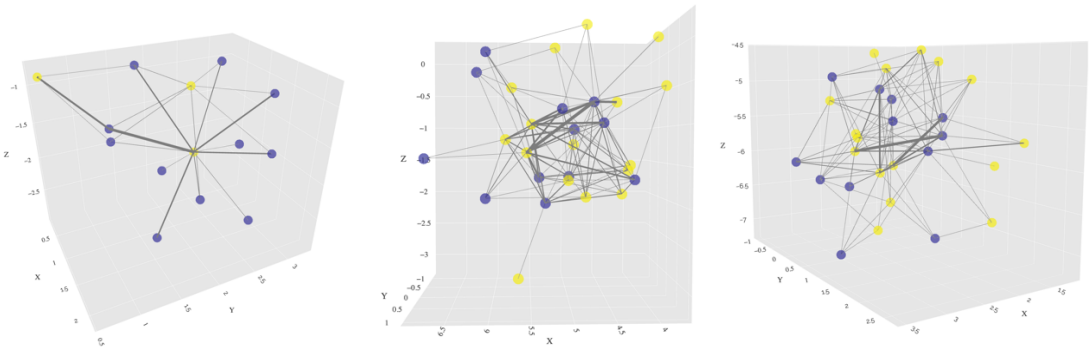
Data source considerations

The UNSW functional network analysis approach currently takes two forms, which are based on data availability. The first form is the online tool used to visualise market structure known as the Functional Network Analysis Dashboard (FNAD).

The second form of functional network analysis is an academic demonstration of its use based on survey data collected by UNSW. However, as the data set was limited the conclusions do not go beyond a proof of concept. This form academically demonstrates that the FNA process is an effective approach where complete datasets can be used. In this section we will explain both forms of functional network analysis more fully.

Functional network analysis requires data about human services being purchased or used by people with disability. As with all mapping tools, the accuracy of functional network analysis depends on the quality of data that is draws from, and thus questions of data infrastructure and linking capacity between data sets are essential for the success of functional network analysis, and indeed other service mapping efforts.

Figure 6 *Example graphs from the functional network analysis dashboard (FNAD)*



What is functional network analysis?

Functional network analysis is a form of network analysis that focuses on 'functions' of a service sector rather than individuals or organisations. An important conceptual shift within functional network analysis and the Dashboard is to take types of disability and types of disability service as units of analysis rather than organisations or individuals, allowing for the structure of markets to be understood, highlighting ones which might be 'thin', failing or in some way problematic (i.e. consumers do not have choice and control over the services they use, as envisaged under the NDIS, because of a market deficiency such as low levels of supply or undifferentiated supply).

When used in the context of the NDIS, the focus of functional network analysis is on understanding the linkages or relations between service provider categories and primary disability categories. But rather than looking at connections between specific service providers or service users, functional network analysis takes the unit of analysis to be the interactions between categories of disability and categories of service providers (currently based on NDIS plan categorisations). While functional network analysis currently uses categories of disability based on NDIS categories and disability diagnosis, these categories are flexible based on available data. For example, when the NDIA adopt different needs assessment, the functional network analysis can be flexible to these new ways of categories. In this sense, functional network analysis could be used to map other service systems beyond the NDIS or disability services.

Information the FNAD provides

The most advanced FNAD work has been developed by UNSW and NSW state government to meet needs around the identification of thin markets. The co-production of the FNAD shows that the approach is flexible and customisable to several different visualisation options based on data availability, (e.g., adding a filter for inclusive or culturally appropriate services).

Currently, the functional network analysis dashboard features the following matrices:

- *Number of claims* – this graph shows the number of claims made between disability type and service type.
- *Total cost of claims* – this graph shows the total cost of claims made between disability type and service type.
- *Average cost of claims* – this graph shows the average cost of claims made between disability type and service type. This graph visualises the total $ cost of claims divided by the total number of claims by each support category and disability type.
- *Average utilisation of claims* – this graph shows the average utilisation of claims made between disability type and service type. The average utilisation of claims is calculated as the amount of money spent from a plan line item divided by the amount of money that is allocated to that line item.
-

The strength of the dashboard is in its ability to visualise and communicate existing data. It offers a process of analysis that results in potential thin markets. These markets can then be further investigated for whether the potential thin market presents a problem or issue for NDIS participants. With greater data availability, more functionality could be built in. This could include inclusivity (i.e., availability of services for specific cultural groups or high need groups) and socio-economic demographics.

Enhanced potential of the FNAD

The FNAD approach is scalable to every LGA in Australia, or by postcode.

The current iteration of FNAD has been developed with NSW state government and is able to be further developed for various market stewardships purposes. The FNAD is flexible and customisable to a number of different visualisation and analysis options based on data availability, (e.g., adding a filter for culturally appropriate services). The case study questions from the DPC scoping document are addressed below:

Location and geography

Functional network analysis visualises market structures. Importantly, functional network analysis *does not* analyse on the basis of the geographical address of service providers. This is important because while some services need to be delivered and situated locally, others do not (e.g., a telehealth survey or purchasing of a product or aid). And in some instances of service provision is not the site of service delivery.

In the case of the NDIS and work with NSW government, we have worked within postcode/LGA levels as this is what has been requested. In this sense, FNA can be used at whatever granularity data is available at, or inversely at a much larger scale (e.g., Australia wide maps could be generated).

Inclusiveness

The functional network analysis approach can easily visualise the inclusivity of services, given the available data. Inclusivity of services may relate to, for example, the cultural appropriateness of service providers, services that are approved to work with complex behavioural needs, or the languages in which a service may be offered. The UNSW dashboard already works using a set of filters, currently used to filter by LGA or type of disability, and this function can easily be adapted to filters based on culturally appropriate services, language, or other inclusivity concerns. The FNAD offers the potential to visualise inclusive service markets, depending on data availability.

For example, if providers were accredited as competent and inclusive for particular groups, a filter could be built which would show a market map which contained only accredited services.

This is important because a market/service system may seem robust but is in fact 'thin' or failing for specific groups.

Primary uses

The FNAD approach is applicable to NDIS related data, and it is also applicable to data outside of the NDIS if such data is available. Specifically, the approach looks at connections between service users and service providers and can be applied to data that shows a relationship between users and service providers – this relationship may be service uptake, service wait lists, NDIS plan utilisation rates and so on.

Limitations

The current limitations of functional network analysis are that:

- It can provide an indication for a potential thin market, but it not an absolute diagnosis of a thin market. Rather it is the first step in understanding where to look for thin markets, and a good tool for communicating about thin markets
- The findings depend on quality and availability of data, while there is good data about NDIS services, there are less thorough records of the use of services outside the NDIS.
- The FNAD does not currently map according to geography, however this may be explored if needed.

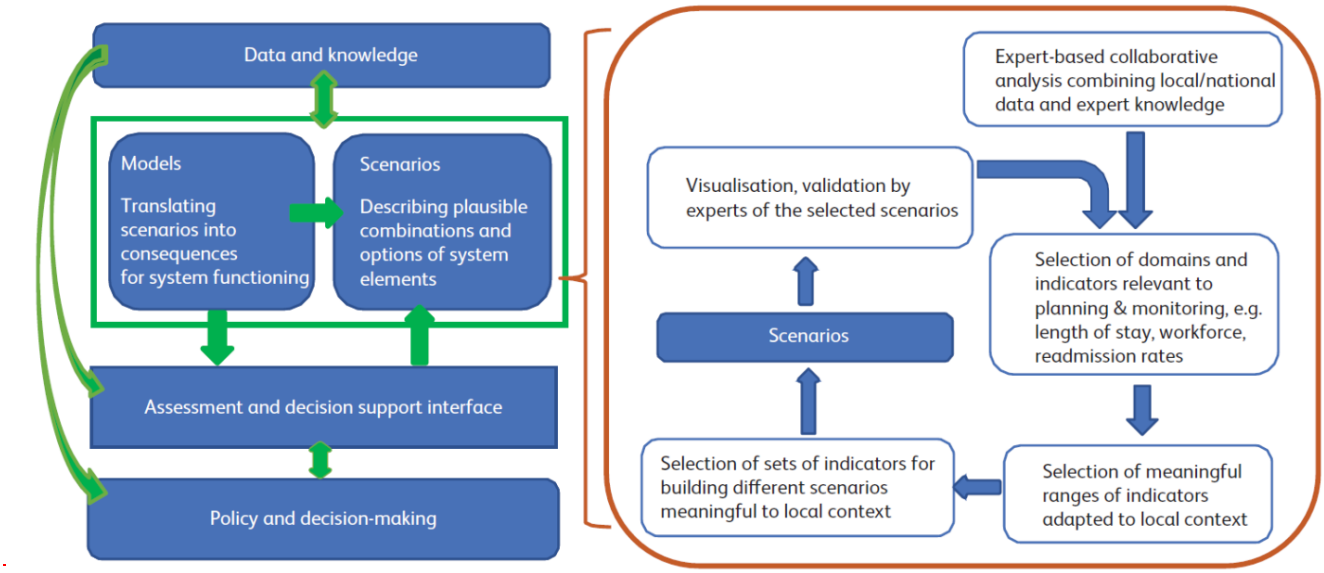
Tool 6: Modelling for Support Decision Systems

I. Purpose

Increasing knowledge of the local context can inform more reliable modelling of scenarios to enable appropriate implementation of general or universal knowledge and more efficient targeting of interventions (Chung et al., 2018b; García-Alonso et al., 2019).

Figure 7 below shows the process of incorporation of data and expert knowledge in scenarios and models that can be converted into decision support systems for informing health planning

Figure 7. The process of using modelling and scenarios to transform data into knowledge for evidence informed planning within a Healthcare Ecosystem perspective (Furst et al, 2020).



II. Data utilised

Models can incorporate all sources of available data on the context, inputs, throughput and outputs in the process of health care and social support services. However, the more important aspect is the combination of data analytics and expert knowledge to interpret complex information and to formalise knowledge for improving the scenarios and the assumptions incorporated as rules into the modelling process.

III. Data source considerations

There are several methods to combine data mining and expert knowledge in a process called “Knowledge Discovery from Data”. In our case we have used extensively an approach called “Expert-based Collaborative Analysis” (EbCA) (Gibert et al, 2010).

IV. Information the tool provides

The use of modelling tools has primary advantages for the analysis of health and social systems, and secondary benefits for guiding the policy decision making process.

V. Primary uses of the tool (relevant to decision making)

From a research perspective modelling can:

(1) generate and verify hypotheses

(2) express interest through the process of Knowledge Discovery from Data (KDD)

(3) specify information processing and present outcomes of analytical reasoning processes

(4) identify hidden information and elicit tacit knowledge that can be formalised and transformed into rules for further data analysis (Chung et al, 2018)

(5) facilitate knowledge transfer between researchers and policy makers

VI. Enhanced potential of the tool with additional information

From a policy and managerial perspective modelling can:

1. Identify ways of improving service performance
2. Reduce uncertainty by increasing information on the health system
3. Identify the key determinants factors of efficiency within a system
4. Describe complex service performance for benchmark analysis
5. Help policy makers to achieve greater system understanding
6. Improve services and resources allocation and management

VII. Limitations

All the challenges for the adoption of service mapping described above (section xx), are applicable to the use of modelling in decision making. The major risks are related to the "once-size-fits-all" fallacy. That is, thinking that a single model can answer all the question of a system. Usually different models provide different perspectives for guiding the same problem. In other occasions a problem can be decomposed in a series of questions that require different modelling techniques and also different scenarios (different combinations of variables analysed in the simulation process). Modelling also requires the environmental/healthcare ecosystem approach mentioned above. Finally modelling could be regarded as the epitome of disruptive innovation in social planning.

VIII. Case examples

Growing Hierarchical Self-Organising Map (GHSOM)

Health and social experts are required to reach deeper knowledge on service planning for healthcare improvement. With the growing availability of health and social support systems data, the analysis of care patterns, care equity, coverage, access and met and unmet needs demands a better combination of expert knowledge and data analytics in service planning. However, the data complexity with high uncertainty makes health and social planners difficult to understand their systems. This requires experts to be engaged with the application of advanced methods that can guide their complex data analysis and evidence-informed decision-making processes.

Growing Hierarchical Self-Organising Map (GHSOM) is a visual analytics model based on machine learning algorithms and appropriate visualisations includes an algorithm for machine learning and user-friendly visualisations for guiding expert-guided data analysis. This tool has been applied to the hierarchical pattern analysis of two systems for psychosocial disabilities: community mental health care in the Basque Country (Spain) and supported accommodation in England.

This system facilitates planners to be engaged with the application of advanced methods that can guide their complex data analysis and evidence-informed decision-making processes. It can enable health experts to interactively take the processes and develop their knowledge for decision support.

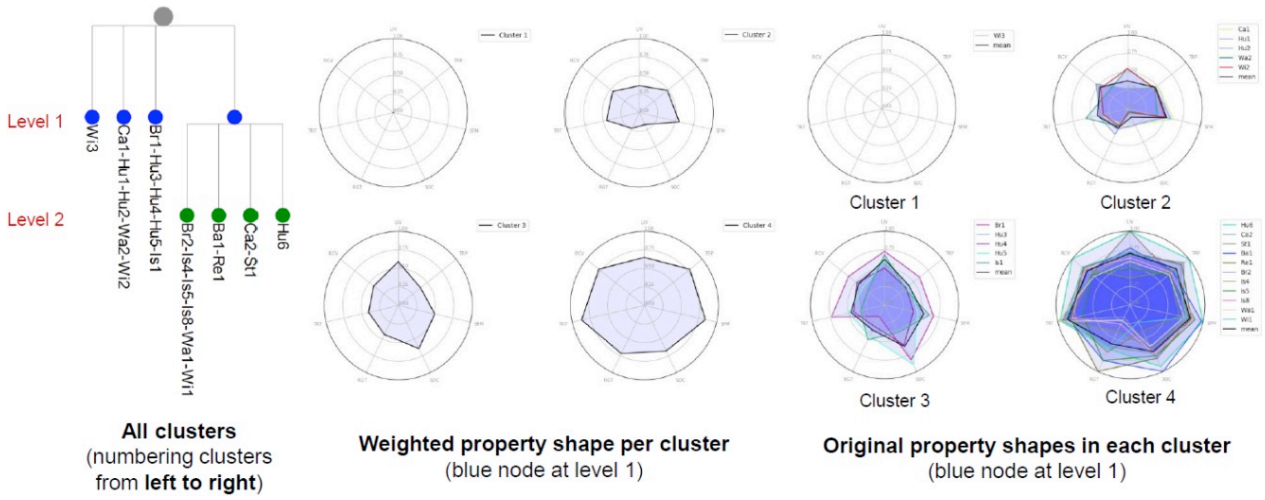
The analysis of the care provision of Mental Health in the Basque Country (Spain), comprised a total of 32 catchment areas with 64 key performance indicators describing service resources and utilisation. This study conducted four different pattern analyses on resources and utilisation for two types of services (inpatient care and outpatient care) to assess care equity of the mental healthcare services at micro (individual services in a system), meso (between systems) and macro (for a region) levels.

The visual analytics tool effectively facilitated the expert-guided hierarchical pattern analysis of complex mental healthcare services. The inherent patterns of resources and utilisation for each of inpatient and outpatient care services were visually identified at different cluster levels and compared at different analytical levels with interactive expert interpretations. Processing and reasoning the visual pattern information, the health experts were able to deeper understand the mental healthcare systems and assess care equity of both service types, taking the regional area characteristics into account. The tool contributed to the increase of evidence-informed expert knowledge by reducing uncertainty about complex mental healthcare systems.

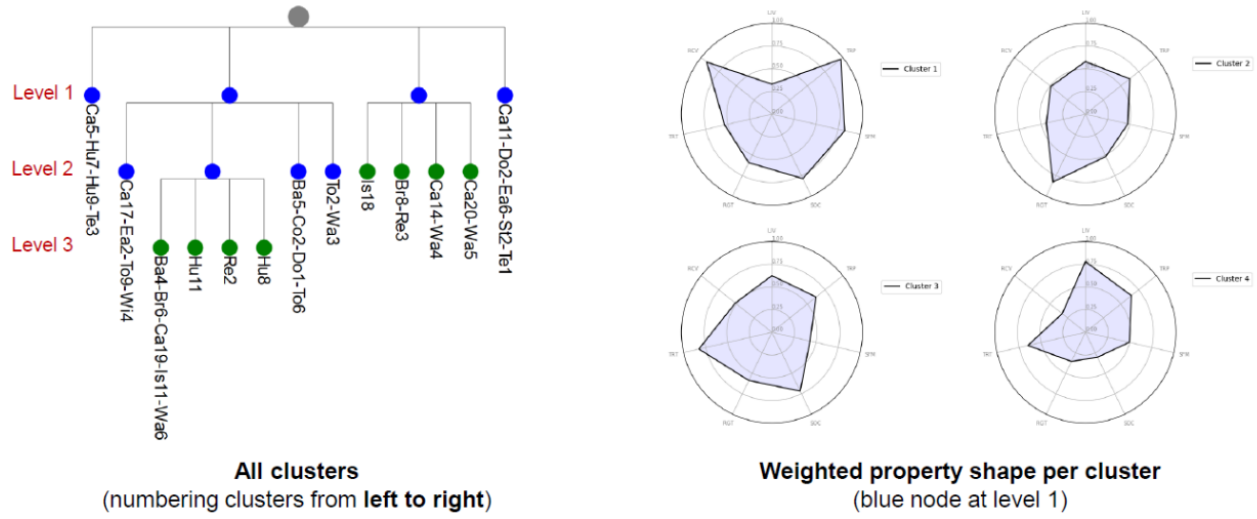
The hierarchical clustering visualisation and analysis of supported accommodation and housing support from Psychosocial disabilities in England is provided in Figure 8. This approach identified four major types of services in supported accommodation that followed a gradient in the ratings obtained in 6 main domains of quality. Cluster 1 included only one service that should require an audit and probably restructuring. Clusters 2 and 3 included services with different strengths and weaknesses in relation to the domains of quality and cluster 4 grouped the services with higher level of quality in most indicators. This shows the usability of this approach to identify typologies of social care from data and not from pre-established administrative categories.

Figure 8. Hierarchical clustering of Supported Accommodation services in England

Supported Accommodation



Supported Housing



Efficient Decision Support tool– (EDeS)

EDeS is a modelling tool for Relative Technical Efficiency Analysis (RTE) for guiding evidence-informed planning. Relative Technical Efficiency Analysis is one of the main tools of causal modelling for supporting planning and management of health and social services and systems as shown in a recent systematic review in mental health [21]. EDeS-MH is a simulation model developed by the University Loyola Andalucía in collaboration with ANU. and its practical use for guiding evidence informed planning has been tested in several regions in Europe such as Catalonia and the Basque Country in Spain [22](Garcia-Alonso et al, 2019), and in England for the analysis of supported accommodation in Psychosocial disabilities.

RTE analyses the relationship between (weighted) inputs (resources) consumed and outputs (resource utilization and outcomes) produced by a set of comparable Decision-Making Units (DMU). It is "relative" because it is obtained by comparing every DMU to each other. It uses a Monte Carlo Data Envelopment Analysis tool combined with a fuzzy engine. The technical characteristics of this RTE model for regional policy and planning has been published by our research group.

As an example, the analysis of the overall technical efficiency of catchment areas of mental health care in Gipuzkoa (Basque Country) identified the benchmark cluster (areas 3, 4 and 11), as well as other clusters with different patterns of inefficiency in relation to different types of care provision (hospital, outpatient and day care) (Table 3).

Table 3 Probability of having an RTE greater than 0.75. In green the best scores and in red the worst.

$P(RTE > 0.75)$	**Acute hospital care scenario**	**Day care scenario**	**Outpatient care scenario**
Area 1	1.000	0.000	0.000
Area 2	1.000	0.000	0.000
Area 3	1.000	1.000	0.996
Area 4	0.998	1.000	1.000
Area 5	1.000	0.000	1.000
Area 6	0.998	0.000	0.436
Area 7	0.000	0.000	1.000
Area 8	0.782	0.000	0.550
Area 9	1.000	0.000	0.162
Area 10	0.904	0.000	0.910
Area 11	0.994	1.000	0.998
Area 12	0.006	0.034	0.778
Area 13	1.000	1.000	1.000

Key: Light Semaphore: In green the best scores and in red the worst

RTE is useful for the following tasks:

- To identify ways of improving mental health and social service performance
- To reduce uncertainty by increasing information on the health and social system
- To identify the key determinants factors of efficiency within a system
- To describe complex service performance for benchmark analysis
- To help policy makers to achieve greater system understanding
- To improve resources allocation and management

4. What are the main challenges to adopting service mapping?

Despite the values and advantages mentioned above, there are a series of challenges and barriers for the adoption of service mapping and the related decision support tools in care planning. These barriers can be linked to general and technical challenges, as well as procedural challenges.

3.1 General challenges

Broadly, we describe four key general challenges to the use of information for care planning. We also briefly refer to alternative approaches or solutions to overcome these problems. For a more detailed explanation, refer to Appendix 1 (Explanation of the main challenges to adopting service mapping).

1 The 'One size fits all' fallacy

The challenge: Decision systems cannot be designed as if there is always a single user (e.g., a planner at a national agency), working with a single problem (e.g., the development of national indicator report card for monitoring performance). The one planner–one problem paradigm is the main guiding principle of evidence-based planning approach, that uses a specialised framework of the PICO question (i.e., Problem, Intervention, Comparison, Outcome) to guide literature search and decision making. PICO questions also lead to designing objectives that are either too specific or too broad to be applicable to real world problems. Importantly this evidence-based approach largely ignores the fact that systems are complex, and therefore bound to uncertainty, time and context variation, and unpredictability. The traditional "evidence-based" perspective relying on randomised control trials has recently been replaced by a broader systems thinking approach that has incorporated context, routine data, simulation, modelling and forecasting [23].

An alternative or solution: The 'Building block' approach to toolkit development and planning

Real world solutions should encompass multiple perspectives, multidisciplinary teams, and a broad span of recipients of the information. The goal of any evaluation in the real world is not to identify the "true" solution to a single question with the highest level of accuracy, but to identify key areas of improvement and set the prioritization sequence of steps to achieve it, while increasing team's learning and capacity to drive change.

A valuable example of the building blocks strategy to service design is the LEGO approach [24]. It has a major focus on a systematic documentation of processes to:

a) Capture knowledge

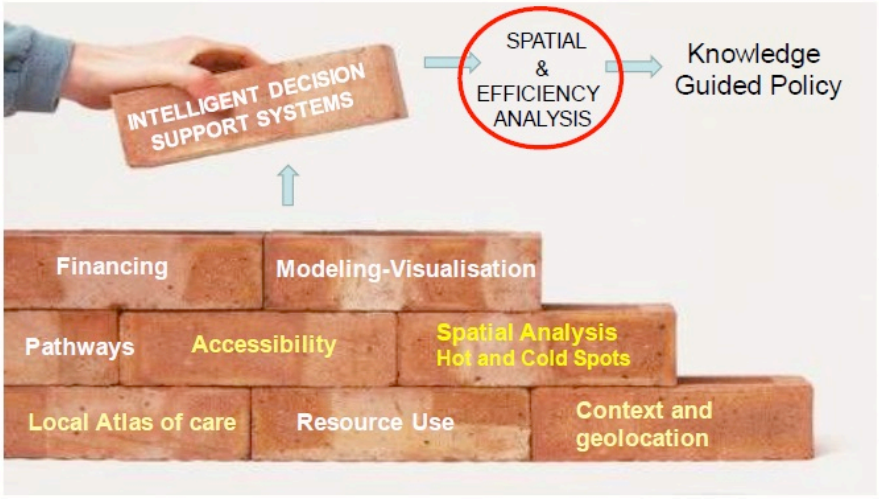
b) Share knowledge in a structured way

We show this 'building' block approach

c) Establish a foundation for process optimization.

In our case (service mapping applied to decision support systems), there is no one type of service map or visualisation that can answer all the questions relevant for integrated value-based planning. Mapping is best approached as a toolkit, i.e., a series of approaches that can provide information to answer different questions or be used by different groups. The tools are like bricks in a wall, which can support decision-making at various levels as shown in Figure 9.

Figure 9 Building Blocks for Effective Decision Support



2. The ecological fallacy

The challenge:

The ecological fallacy assumes that general population means and national averages of prevalence, service availability and capacity apply directly to individuals or local services. On the contrary, local, state and national indicators can only be usefully understood within specific environments and contexts. Moreover, the risk of only using "average man" indicators can also objectify language, treating a defined group of persons with severe disabilities as the beds they occupy in community residential settings, or as their functional level of severity, when their needs and preferences should be our "Pole Star" from a person-centred perspective.

We know in Australia how confusing the translation of the national picture to the local context can be, with multiple funding sources and programs, public and private, state and federal and so on. It is critical to understand the local system, particularly to avoid perpetuating confusion or creating inappropriate incentives that may work in one setting and become a perverse incentive or even a barrier in another.

An alternative or solution: The healthcare ecosystem approach to care planning

The healthcare ecosystems approach views the context of care delivery in an specific area (e.g. a district, a region or a state) from its whole systems perspective [25]. It is an approach which recognizes the limitations of traditional, more linear, research methods in the analysis of situations of complexity such as the environment and context of health and social systems. Within complex systems such as these, comprised of diverse and interacting elements, service policy, planning and outcomes are not always predictable and may lead to unintended consequences [26, 27]. Reducing the level of uncertainty is achieved by any information and means that increases our knowledge of the whole system and its behaviour.

As a first and fundamental step, this includes knowledge of the context : the boundaries of local system, the description of its population including social and demographic factors as well as the lifestyles; the characteristics of the specific agents and actors (e.g. persons with disability, their carers, the professionals and the provider organisations); the structure of care and support (what services are available, where they are and what they are doing) and the connections between actors, agents and organisations. Good planning will also require many other sources of information such as the quality of the provision and the financial flows affecting funding across the system (e.g., a health district or a region). However, these different components can be achieved and refined step by step.

To map provision to needs, it is necessary also to build a picture of both existing (where people go now) and desired (where people want to go or should go) pathways of care within the region in question and to consider current issues of accessibility. Refer to Appendix 1 for an example of the ecosystem approach in mental health.

<u>The terminological fallacy</u>

The challenge:

Although we take for granted that the names we use in plain language are universal, their meaning varies hugely. Any sector, from science to law and business, needs to avoid vagueness to communicate effectively. A terminology or classification are not jargon, but critical tools to develop and use precise terms. We assume that administrative listings of services provide reliable and accurate information of the local provision of care, and that this information can be directly used in the analysis of gaps, financing, unmet needs, modelling and planning. This assumption ignores two facts: a) the official name of a service does not reflect its activity, and b) “services” are not “brick and mortar” facilities, but very complex and heterogeneous human organisations where finding comparable unit of analysis is a hard task.

In social and health care identifying workable units of analysis to make service comparisons like-with-like is particularly difficult. Terms used to describe the sector are frequently ambiguous and confusing. An example of terminological ambiguity is the different uses of the term “service” and the implications this has for interpreting evidence and for prioritisation and planning.

Service be an **activity** (e.g., doing work for someone such as personal assistance with showering), or an **organisation** (e.g., an attendant care service). This double meaning of "service" could be regarded as one of the main barriers to service improvement as they are completely different units of analysis, that use different classification systems and that cannot be merged in system planning. Of course, both the interventions and the services where these interventions occur should be counted, but they use different classifications.

An alternative or solution: The disambiguation process.

Uncertainty in information and databases constitute a major focus of concern for public agencies [7].This uncertainty is generated by the lack of a common language. There is need for "disambiguation" (by making it clearer, reduce the ambiguity and vagueness in terms) before the available information can be meaningful and used effectively to guide planning. The use of codes instead of names could facilitate planning where names themselves have become barriers for communication across sectors or disciplines.

There are several classifications that the service mapping can used. A few examples of international classifications are interventions [WHO International Classification of Health Interventions (ICHI)]; services [DESDE (Description and Evaluation of Services and DirectoriEs)]; person-related functioning [WHO, International Classification of Functioning (ICF)]; health conditions (WHO International Classification of Diseases (ICD-11)]. Some of the six mapping tools use international classifications and so can 'talk' to each other.

Disruption of innovation effects in service mapping

The challenge:

It is generally accepted that the adoption of new service mapping technologies is the way forward to overcome discretionary planning. However, service mapping technologies do not stand alone and are basic components of multimodal decision support toolkits for evidence-informed policy (see Figure 9). This function goes beyond incorporating a new technology into a traditional planning process. It implies a transformational change of how we think and enact planning, that requires a different mind-set moving away from best practice standards to fully embrace systems thinking and complexity [28]. As such, it does not only involve change; it is a process of disruptive innovation [29]. This disruption involves all aspects of the process, from its conceptual framework, to the sources of information; the data production, processing and interpretation; and the knowledge generation, application and impact analysis.

Four main questions have been formulated to understand how organisations confront and thrive in a disruptive innovation environment (Box 3).

Box 3. Four basic questions to thrive in a disruptive innovation environment

- Can you see disruption coming?
- Are you looking outside your field?
- Is your organisation communicating its purpose clearly?
- Are you fighting complacency?

The 2018 Ernst and Young Report provides a useful roadmap for companies facing a disruptive innovation environment [30]. This framework could be adapted to organisational changes in social and disability planning.

***The solution**:* Systems thinking for Decision Support Systems care planning

The adoption of disruptive innovation requires a system thinking framework. Within this framework the ultimate goal of data analytics is to reduce uncertainty and to increase organisational learning, rather than providing a "true final answer" to a single question. The description of the theoretical background behind systems thinking applied to service planning has been reported in a series of papers and technical reports that are available for further scrutiny [23, 28, 31, 32].

The context of health care delivery plays a critical role in the analysis. The "whole system" approach intends to provide a description of all services available for a target population regardless of its regulatory or funding agency [25]. Thus, an integrated map should include services from the disability and social sectors, as well as health, justice, employment, education, and housing. It recognizes the limitations of traditional, more linear, research methods in the analysis of situations of complexity such as the environment and context of health and social care systems [28]. Within complex systems such as these, comprised of diverse and interacting elements, service planning and outcomes are not always predictable and may lead to unintended consequences [26, 27]. Reducing the level of uncertainty is achieved by increasing our knowledge of the whole system and its behaviour using an ecosystem evaluation. As a first and fundamental step, this includes knowledge of the structure of the system: what services are available, where they are and what they are doing.

<u>Key messages</u>

Over the last 20 years, members of this team have provided extensive evidence of the application of service mapping and the related Decision Support tools in real world environments. The tools outlined in this report draw, broadly, on the systems approach (though different tools have specific methodological underpinnings, described under case studies in later chapters). Some general principles can be drawn upon this experience:

- A healthcare ecosystem approach should be adopted
- A common language should be developed.
- The processes involved should be transparent and open to scrutiny.
- The tools should be tested and proven in relevant real-world environments[1]
- A separate and detailed analysis of the impact should be conducted.
- Results should be comparable across jurisdictions and over time

[1] The tools and the results of their implementation should be published. Only results in peer-reviewed publications should be regarded as scientific evidence (i.e., evidence that can be contrasted, corroborated, replicated and reproduced). The tools should be flexible, adaptable, transformable, and dynamic. Ideally a continuous improvement process should be designed and implemented.

4.2 Technical challenges

Health and social care sectors are comprised of many different elements operating at different levels of a dynamic system. These include a broad range of professionals working in a number of different service types; the diverse ways in which disability presents and the contextual impacts that affects people, including impacts on functioning, activity and participation. Contextual factors which impact include the geographic, socio-demographic and socio-economic characteristics of the local region, including those which have a particular relevance to disability, such as social isolation. This complexity has contributed to methodological issues in health and social support system research.

Onto- terminology tools

The challenge:

The first technical challenge is the lack of tools that enable using a common language. This includes an explicit frame of reference, a taxonomy, a coding system and a glossary of terms to describe elements within the system, as well as the standardised units of analysis with which to classify them. The new discipline involved in the study and the development of these instruments is called "onto-terminology" and it plays a critical role in disambiguation. When available, these tools facilitate communication across different sectors, professions, stakeholders, organisations, jurisdictions and databases (see "semantic interoperability" below).

The solution:

i) Data infrastructure – for human service mapping for people with disability

The validity and reliability of mapping and visualisation efforts are contingent upon the data that they are drawn from. Issues of data infrastructure are essential for the National Disability Data Asset in Australia. Some key considerations for data infrastructure are:

- What is wanting to be known? Does data exist to answer that?
- What data is currently available and who stores it?
- What additional data should be collected? How can it be linked to existing data?
- Will it be administrative data (e.g., data collected by other systems while delivering services)?
- Will administrative data need to be augmented? (e.g., with qualitative research, or more detail than what would normally be captured administratively without planning for data mapping or visualisation)
- Is that data identifiable/de-identified or re-identifiable?
- Who owns the data? e.g., an agency, a state government, the commonwealth government
- What is the data linkage capacity across different data assets?
- How is that data governed?
- Who will be given access to it?
- Can we anticipate service usage based on previous usage?

The answers to each of these questions determines what maps and visualisations can be built, and the reliability of what they show. A list of some of the existing data sources relevant to people with a disability is provided in Appendix 2.

There are a range of limitations with existing data infrastructure in Australia. Most service information available is comprised of inadequate directories or official lists of preferred/approved or registered providers, with a limited few providing further detail on skills. None of the lists currently available are fit for purpose for planning, identifying market gaps and development, nor empowering participants to choose the service they need. The location of the organisation does not reflect the actual location of where the service is provided, nor potential location, although some directories/portal provide information on the service region. Finally, descriptors of service and interventions provided by the organisation may not always reflect actual service. These challenges are not insurmountable but need to be addressed in the construction of a national data asset.

Other points for consideration include:

- There is not one system of services for people with a disability, rather an ecosystem where needed services are across all sectors and levels of care, be they inclusive in mainstream or specialist services.
- Often what is missing about service information is the capacity of mainstream services to support people with disability. For example, there are different levels of support services for a child with a disability at school which are: schools for specific purposes, specialist support classes within schools and itinerant support teachers, which reflects the level of support the child may need. Typically, the current sources of information are incomplete lists of some of the specialist disability services, and not the capacity of mainstream services to support people with disability.
- There is no information from any source which provides a measure of service stability (e.g., sustainability of a service beyond 3 years of funding).
- The language used to describe services in the existing databases is ambiguous and inconsistent, thereby preventing comparing or grouping 'like with like' services at any level is not always possible. As said, comparisons and identifying gaps can be achieved with the use of a standard language (taxonomy) and agreed framework. This is important for some, but not all, mapping techniques.

ii) Linking administrative data

Maps of the availability of services should be linked to the utilisation of these services by the target population. To achieve this, it is important to be able to link multiple administrative data sets showing service usage across agencies and levels of government. There are different levels of data linkage.

At a *first level*, data linkage occurs through the **probabilistic matching** of records. Probabilistic matching links records in different datasets that have the greatest probability of belonging to the same person. It uses several identifiers such as date of birth, gender and address to identify and evaluate the similarity of links.

A probabilistic process weighs the evidence for a link being a match, against the evidence that it is not a match. Further, as time passes personal identifiers such as family name and address can change because of marriage or moving to a new house. This impacts on the quality of data matching. By utilising multiple data fields and developing a packaging of data (syntax), a probabilistic linking process can lessen the effect of these changes and account for lost accuracy. Data is kept secure through encryption processes including the Bloom filter that encrypt identifiable information and then link it before encrypting again.

A *second level* will include datasets linked through **semantic interoperability**. Semantic interoperability is the ability of computer systems to exchange data with unambiguous, shared meaning. Semantic interoperability is a requirement to enable machine computable logic, inferencing, knowledge discovery, and data federation between information systems. Semantic interoperability is therefore concerned not just with the packaging of data (syntax) mentioned above, but the simultaneous transmission of the meaning with the data (semantics). This is accomplished by adding data about the data (metadata), linking each data element to a controlled, shared vocabulary. The meaning of the data is transmitted with the data itself, in one self-describing "information package" that is independent of any information system. It is this shared vocabulary, and its associated links to an ontology, which provides the foundation and capability of machine interpretation, inference, and logic.

A *third level* incorporates fully **integrated digital records**. As an example, NSW Health has introduced the My Health Record system and has approached the market for a single digital patient record (SDPR) to replace the state's fragmented line-up of core clinical and laboratory information management systems. A truly integrated digital record should also incorporate social care. Examples of integrated digital record systems including health and social care are available in other parts of the world. For example the integrated social digital record system in Andalucia (Spain) (DESDE-AND) [33] has developed a coding tool to eventually link service use and service availability in their mapping tool for planning and navigation of their social care system, as well as the linkage to health data.

Linking data at different levels of government requires data sharing agreements enabling unit record level information to be shared between government agencies. A few Australian centres utilise probabilistic matching and anonymisation techniques to link records across multiple datasets. In NSW, The Centre for Health Records Linkage (CHeReL) conducts record linkage for health services as well as other human services data. The CHeReL utilises a Choicemaker software for linkage, standardising and parsing data through an automated blocking algorithm and machine learning technique. Examples of linkage include the CHeReL Master Linkage Key and NSW Human Services Data Set. Appendix 3 provides a list of national data sets and their linkage capacity. Appendix 4. provides a brief overview of the sector and state of play in Australia.

5 Considerations and next steps

This paper has suggested the four basic questions for the assessment of system improvement and leadership. These questions were:

- Do you know how good you are?
- Do you know where you stand relative to the best?
- Do you know where the variation exists?
- Do you know the rate of improvement over time?

This report has provided evidence and practical examples of how these questions can be answered following a building block strategy that incorporates an Atlas of Disability Services. In the past 6 years, there have been several proposals and multiple discussions with key organisations in Australia to fund a 'use case' for mapping disability related support services in Australia, unfortunately without success. A 'use case' of comprehensive service mapping will assist building better understanding of the practical supports and services for people with disability at a local level, highlight some of the critical and influential contextual factors and demonstrate potential linkages with the National Disability Data Asset.

Comprehensive service mapping involves sourcing the information on services from the ground up. The effort involved in data collection of service availability for completing the Atlas, can be significantly reduce by using automated tools for registering and coding services. This information should be completed with data on resource use and outcomes, if possible, agreed in a report card. The information on the service delivery system and its utilization should be represented and geolocated using GIS. The connections across the different stakeholders and actors, and the relationship between consumers and the different sectors can be registered using social network analysis techniques. Finally, the building blocks described above can be incorporated into modelling tools to effectively inform policy and planning. Despite the major advances in service mapping and evidence informed planning, there are major challenges that slows the rate of adoption of this strategy by the public sector. These challenges include the gap between what is the current level of use of these technologies and the ideal goal for any sector and agency, the need of an ecological approach focusing in local areas and context, and the use of systems thinking. In any case the major barrier is related to the fact that the use of these approaches implies a disruptive innovation that in not easy to adopt in the public health and social sectors.

Finally, there are four procedural considerations worth mentioning as next steps for the adoption of this approach to planning:

- Assessment of methodologies depending on the NDDA need and anticipated uses (short medium and longer term)
- Design an architecture and linkage to build – start with a synthesis of qualitative and administrative data
- Assessment and design could see existing service mapping tools scaled
- Future work to include assessment of using a toolkit and pilot to assess

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Appendix 1 Further explanation of the challenges and solutions

The ‘one size fits all’ solution

The “LEGO” approach to toolkit development and planning

Real world solutions should encompass multiple perspectives, multidisciplinary teams, and a broad span of recipients of the information. The goal of any evaluation in the real world is not to identify the “true” solution to a single question with the highest level of accuracy, but to identify key areas of improvement and set the prioritization sequence of steps to achieve it, while increasing team’s learning and capacity to drive change.

A valuable example of the building blocks strategy to service design is the LEGO approach. A relevant example of the application of the LEGO approach to complex problems is “Quartet”, a custom design system for mental health inspired by the metaphor of LEGO building blocks. First it identifies the foundational building blocks as necessary for progress. Second it establishes a common language. Each domain or key component is named in a logical way that points to its use and will make updating these values in the future easy. Then it identifies the “atoms” or basic units of analysis to produce a domain’s knowledge-base that is organized as a components library. Next there is a process of cleaning and simplification and finally it adds a visual perspective (“make it beautiful”).

The LEGO approach underscores the importance of modularity in complex system’s design. In our case (service mapping applied to decision support systems), there is no one type of service map or visualization that can answer all the questions relevant for integrated value-based planning. Mapping is best approached as a toolkit, i.e., a series of approaches that can provide information to answer different questions or be used by different groups. The tools are like bricks in a wall, which can support decision-making at various levels.

The ecological fallacy assumes that general population means and national averages of prevalence, service availability and capacity apply directly to individuals or local services. On the contrary, local, state and national indicators can only be usefully understood within specific environments and contexts. Moreover, the risk of only using “average man” indicators can also objectify language, treating a defined group of persons with severe disabilities as the beds they occupy in community residential settings, or as their functional level of severity, when their needs and preferences should be our “Pole Star” from a person-centred perspective.

The healthcare ecosystem approach to care planning

The healthcare ecosystems approach views the context of care delivery in an specific area (e.g. a district, a region or a state) from its whole systems perspective [25]. It is an approach which recognizes the limitations of traditional, more linear, research methods in the analysis of situations of complexity such as the environment and context of health and social systems. Within complex systems such as these, comprised of diverse and interacting elements, service policy, planning and outcomes are not always predictable and may lead to unintended consequences [26, 27].

Reducing the level of uncertainty is achieved by any information and means that increases our knowledge of the whole system and its behaviour.

As a first and fundamental step, this includes knowledge of the context : the boundaries of local system, the description of its population including social and demographic factors as well as the lifestyles; the characteristics of the specific agents and actors (e.g. persons with disability, their carers, the professionals and the provider organisations); the structure of care and support (what services are available, where they are and what they are doing) and the connections between actors, agents and organisations. Good planning will also require many other sources of information such as the quality of the provision and the financial flows affecting funding across the system (e.g., a health district or a region). However, these different components can be achieved and refined step by step.

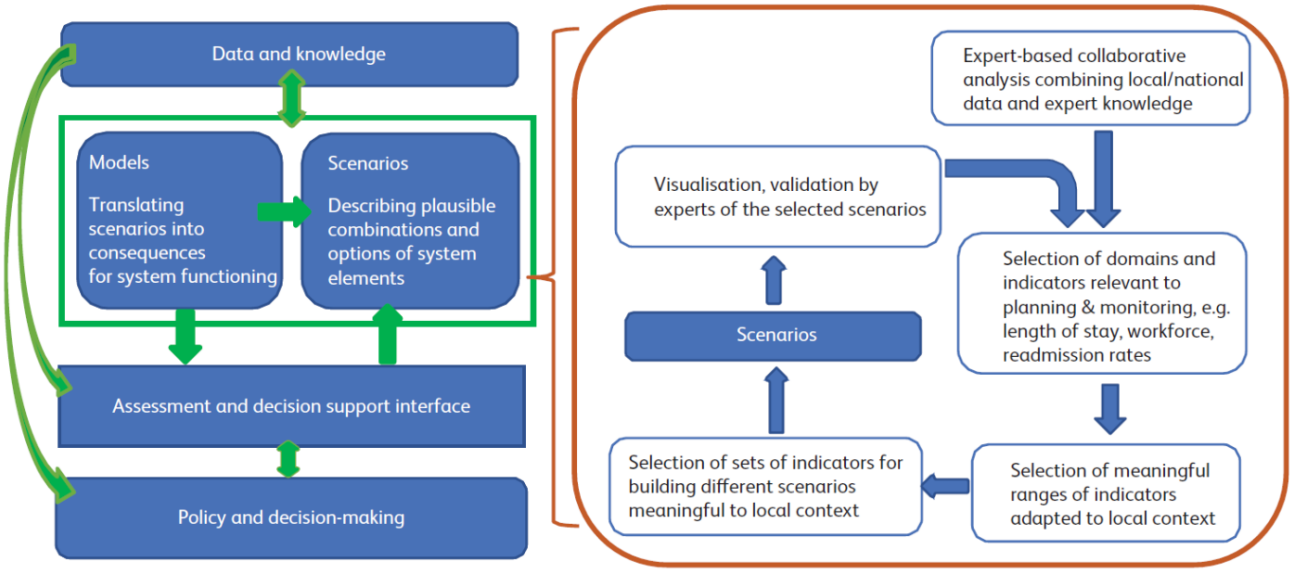
To map provision to needs it is necessary also to build a picture of both existing (where people go now) and desired (where people want to go or should go) pathways of care within the region in question and to consider current issues of accessibility.

An important example of this approach is in relation to mental Health ecosystems research (MHESR), which addresses the complexity of mental health ecosystems. The MHESR research incorporates knowledge from a range of disciplines such as systems theory, implementation science, health economics and context analysis and many forms of evidence including experimental, observational and local evidence along with expert and experiential knowledge [7, 25]. It uses a conceptual framework derived from ecological sciences and the study of biological ecosystems and their benefits to people, health and wellbeing (Ecosystems Services (ESS); adding the resources of mental capital to the other forms of capital (built, social, green) which contribute to human health and wellbeing [34] . MHESR includes a range of tools to gather and interpret evidence from the local context: these can identify gaps in the system, detect patterns within it such as patterns of service availability, enable comparison with other systems, help in understanding geographic variation in outcomes of care delivery, and contribute to the transfer of knowledge between researchers and planners [9, 10, 35]

Increasing knowledge of the local context in this way can inform more reliable modelling of scenarios to enable appropriate implementation of general or universal knowledge and more efficient targeting of interventions [9, 10, 35]

Figure 10 below shows the process of incorporation of data and expert knowledge in scenarios and models that can be converted into decision support systems for informing health planning (in this case in the area of mental healthcare) [25].

Figure 10. Conceptual framework for an Ecosystem approach.



Data Arising from the Case Study

Although we take for granted that the names we use in plain language are universal, their meaning varies hugely. Any sector, from science to law and business, needs to avoid vagueness to communicate effectively. A terminology or classification are not jargon, but critical tools to develop and use precise terms. We assume that administrative listings of services provide reliable and accurate information of the local provision of care, and that this information can be directly used in the analysis of gaps, financing, unmet needs, modelling and planning. This assumption ignores two facts: a) the official name of a service does not reflect its activity, and b) "services" are not "brick and mortar" facilities, but very complex and heterogeneous human organisations where finding comparable unit of analysis is a hard task.

In social and health care identifying workable units of analysis to make comparisons like-with-like is particularly difficult. Over the last 20 years we have identified terminological variation as a problem in every service mapping study we have conducted [8]. In addition, service terms in the social sector are not neutral. Terms are related to framing, labelling and stigma, and therefore they have an ideological, cultural, political, and societal load. When a concept is related to stigma, the load increases over time. Neutral terms coined 30 years ago to name a condition, or a care modality are totally unacceptable today. A typical example is the historical evolution of terms naming intellectual disability and their related services *[36].*

The *Disambiguation* Process

An example of terminological ambiguity is the different uses of the term "service" and the implications this has for interpreting evidence and for prioritisation and planning. Service can be seen as an **activity** (e.g., doing work for someone such as personal assistance with showering), or an **organisation** (e.g., an attendant care service). This double meaning of "service" is could be regarded as one of the main barriers to service improvement as they are completely different units of analysis, that use different classification systems and that cannot be merged in system planning. Of course, both the interventions and the services where these interventions occur should be counted, but they use different classifications. The International Classification of Interventions (ICHI) has been developed to code actions, whilst the international classification of services (DESDE) and the Systems of Health Accounts (SHA 2.0) have been developed to code organisations and their functions. In Australia, NDIS uses "service" as "interventions-activities" and "providers" as "organisations". The Australian Institute of Health and Welfare (AIHW) has its own classification of Interventions that are differentiated from services (Australian Classification of Health Interventions ACHI), and the Department of Health "National Mental Health Service Planning Framework" (NMHSPF) is a typology that uses "services" both as organisations and interventions. It is rather evident that this ambiguity is causing major problems for effective service planning in Australia, and it is far behind the current international terminology used, for example, by the World Health Organisation Family of Classifications that has clearly defined activities as interventions in the International Classification of Functioning (ICHI).

Even if we accept that "services" are the organisations where interventions take place, a further disambiguation is still needed. A generic definition of service as an organisation could be: "Umbrella term that encompasses different units of analysis of organisations in service research". A step further is to provide a workable or "operational" definition of service in a glossary of terms. For example "Within the health sector and the micro-organisation level of care delivery, a service is a combined and coordinated set of inputs (including structure, staff and organisation) that can be provided to different user groups under a common domain, to improve individual or population health, to diagnose or improve the course of a health condition and/or its related functioning"[37].

The absence of agreed operational definitions also influences the definition of professions and professional roles such as "community worker" or "case manager/support coordinator'. The process of developing a common language in disability care is hazardous, but it can take advantage of the existing classifications systems, such as the WHO International Classification of Functioning (ICF) and the International Classification of Health Interventions (ICHI), and the international classification of services DESDE (Description and Evaluation of Services and DirectoriEs). The combined use of international classifications has been recently demonstrated in the disambiguation of "psychotherapy" an extreme case of terminological ambiguity in healthcare [38].

Effects of disruptive innovation in service mapping

While the introduction of evidence-based planning in the 1990s was an improvement of previous practices, evidence-informed planning supported by digital decision tools implies a transformational change of the whole process of decision making. This disruption involves all aspects of the process, from its conceptual framework, to the sources of information; the data production, processing and interpretation; and the knowledge generation, application and impact analysis. This process has similarities to the 'Amazonification effect' on service delivery in healthcare (https://www.visualcapitalist.com/amazonification-healthcare/ .

The relevance of disruptive innovation was first articulated 20 years ago by Harvard Business School Professor Clayton Christensen and its role in service improvement has been extensively analysed under the spotlight of the digital transformation [29, 30]. Not surprisingly, disruption could become a significant barrier to immediate system change and generates gaps across different organisations working in the same sector. In fact, the rapid turnover of digital Decision Support Systems, their technical complexity and the intricacies of their application to real world problems, has surpassed the capacity of assimilation for public health researchers and planners alike. Individual researchers may be overwhelmed when trying to integrate the advance of knowledge in completely disparate research areas; and planners may find these tools difficult to apply in their daily practice.

Decision Support Tool's development can only be accomplished by multidisciplinary teams that ultimately should include service and public health researchers, spatial epidemiologists, systems engineers, health geographers, IT experts, environmentalists, infographers, and consumers and carers. The development and the use of these tools demands new capacity and expertise in the involved organisations that challenges the existing processes and this transformation is mainly at hand in highly dynamic corporations. Telstra constitutes a good case example of this transformational change in Australia [39].

The adoption of innovation tools for planning shows an increasing gap between industry on the one side, and the public sector on the other, with academia playing a bridge role that requires further scrutiny and clarification (for example on its conflict of interest). Typically, tools for service mapping and decision support are developed by companies operating in a "black box" environment, where the underlying algorithms are not available for scrutiny. Of course, there is a knowledge transfer from industry to public planning, mainly through commissioning and outsourcing; but at the end public planning could rely on results that cannot be contrasted in an open environment.

Under these conditions, the huge disparity of quality across different mapping and coding tools is hard to recognise by health and social planners, and this could lead to relying on the infographics more than on the precision of the information represented in the maps.

An example of this tension is the actual value of two different approaches to service mapping: the one based upon existing administrative directories, and the one requiring additional data gathering of service characteristics and coding using an ontology-based classification.

The difference of the information gathered using these two approaches could be compared to the information obtained using a home telescope in comparison to the one provided by the "Hubble" space telescope.

Systems thinking for Decision Support Systems care planning

The adoption of disruptive innovation requires a system thinking framework. Within this framework the ultimate goal of data analytics is to reduce uncertainty and to increase organisational learning, rather than providing a "true final answer" to a single question. The description of the theoretical background behind systems thinking applied to service planning has been revised in a series of papers and technical reports that are available for further scrutiny [23, 28, 31].

The context of health care delivery plays a critical role in the analysis. The "whole system" approach intends to provide a description of all services available for a target population regardless of its regulatory or funding agency [25]. Thus, an integrated mapping should include services from the disability and social sectors, as well as health, justice, employment, education, and housing. It recognizes the limitations of traditional, more linear, research methods in the analysis of situations of complexity such as the environment and context of health and social care systems [28]. Within complex systems such as these, comprised of diverse and interacting elements, service planning and outcomes are not always predictable and may lead to unintended consequences [26, 27]. Reducing the level of uncertainty is achieved by increasing our knowledge of the whole system and its behaviour using an ecosystem evaluation. As a first and fundamental step, this includes knowledge of the structure of the system: what services are available, where they are and what they are doing.

Appendix 2. What are the current sources of service Information?

- For the public NDIS provides - a list of basic information of registered provider organisations in a word or PDF document (name, location, contact details, website per service registration category (related to billing code) or name of the organisation. Participants can access the same information via online location search with some minor additional descriptors of the range of services.
- Icare NSW provides publicly searchable portals of service organisation information on Case managers, attendant care providers, equipment and equipment maintenance providers. The portals are publicly accessible and searchable by location, category of support information, about the organisation, descriptors of staff skill based (e.g., registered nursing).

- Other potential sources of service information can be obtained from
  - Most professional health practitioner associations have a publicly searchable "find a" portal for registered *private* practitioners which provide information on name, organisation, areas of speciality and contact details e.g., Australian Psychological Association
  - The aged care system (Commonwealth and State) which does provide basic listings of information on services for people with a disability (e.g., nursing homes).
  - Information on services for children with a disability under 7 years (excluded from the NDIS). Is available through the relevant sector peak organisations e.g., education, early intervention and childcare services. Many are mainstream services or mainstream with specialists supports. There are some services available through publicly searchable websites e.g., playgroups for children with special needs.
  - NSW Department of health provides limited lists of services within the sector and specialist service networks directories e.g., brain injury

<u>Sources of service use data from specialist services for people with a disability</u>

In terms of Commonwealth service use information (relevant to our example of NSW), per postcode there is:

- NDIS participant health related and support services paid. Payments for services should be used, rather than costs for planned services. The recent Tune review (2019) identified that almost one third of participant funds (31%) were not used in large part due to barriers on the information and access to services they needed [40].
- Complex support needs pathway for young people in nursing homes to plan and exit nursing home accommodation (funding via NDIS)
- Disability Employment Service Program (DES)
- Supported employment/Australian Disability Enterprise (DSS)
- Employer assistance (one off wage subsidy scheme for people with an intellectual disability)
- Disability Support Benefit (income support)
- Disability Parking Scheme
- Better start for children with a disability initiative (funding for children with developmental disabilities to access early diagnosis and treatment)

- National Companion Card (enables attendant carer to accompany the person with a disability to venues and activities without having to pay for the carer).

At the NSW state level

- Icare participant health and support related services paid.
- Integration funding support for schools (NSW Department of Education)
- Taxi subsidy scheme (subsidy of 50% of taxi fare) for eligible people
- Public housing specifically where there has been modifications indicative of home modifications for access (reflective of some people with physical impairments).

NDIS Data

- information of registered provider organisations. The publicly available list of providers by State requiring manual search. It is a downloaded PDF of a 343-page spreadsheet which groups providers into service registration categories e.g., accommodation, assist/access/maintain employment, assistance productivity or personal care/safety, assistance life stage, transition, personal mobility equipment etc. The document provides the name, location, contact details and website link. There is another version of the same document by name of providers. The second option is available to participants only. After logging on, there is a searchable database by location (participants address) with the same information of local services, plus additional descriptors of services (supplied by the provider) on the "view details link'.

- Anecdotally the NDIS is reported to be referring to a website to assist participants to search for providers https://clickability.com.au. The service organisation voluntarily registers on this website. Some mainstream services are listed e.g., Penrith Council, but little information is provided on whether they provide disability services. The website is searchable by the public on location, NDIS registration, specialisation and age group, service category (daily living and access, information and advocacy, education and jobs etc and access method (telehealth, home visit of office etc). There are limited services in their database it seems. The NDIS Quality and Safeguards Commission registers and regulates NDIS providers, oversees provider quality and compliance with practice standards, and reportable incidents worker screening.

icare NSW Data

icare provides publicly searchable portals of service organisation information on:

- Case managers – the portal has information on location, name of practitioners (rather than service organisation), contact details (including phone), category (adult or child), professional information and specialist skills per health condition (provided by the practitioner), and time availability e.g. https://www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/case-managers/find-a-case-manager/m/margot-lilley. The case managers undergo a rigorous quality appraisal and approval process prior to being able to work with participants of icare.

- Attendant care provider (organisations that provide community support workers for personal care, domestic assistance, home rehabilitation supports and community activities). The portal is a publicly searchable database with information on location, contact details, category of support required (i.e. physical support, clinical/high level support, cognitive and behavioural support, registered nursing), information about the organisation and descriptors of staff generally and specialist services (provided by the organisation), office hours https://www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/attendant-care/find-an-attendant-care-provider?f=6FAA319DEFCA4C1A9D75545302139A36&al=2127&alF=Sydney+Olympic+Park+NSW+2127.
- The attendant care providers undergo a competitive tender and quality appraisal process to be on the panel of providers for participants. The panel is reviewed
- Equipment and equipment maintenance provider portals that are appointed to supply people with routine and standard equipment quickly and easily (an 'easy order system". Purchase of other specialist or modified equipment occurs outside of these providers where necessary. There are four providers with brief descriptions, and links to their websites. https://www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/equipment-and-maintenance.

NSW Department of Health Data

- Most professional associations have a publicly searchable "find a" portal for registered private allied health practitioners which provide information on name, organisation, areas of speciality and contact details e.g. Australian Psychological Association https://www.psychology.org.au/Find-a-Psychologist : Australian Association of Occupational Therapists https://www.otaus.com.au/find-an-ot.
- Early childhood early interventions services https://www.hoi.com.au/projects/item/early-childhood-intervention-australia-ecia-2

Appendix 3 Sources of data identified by DPC to be linked

Dataset	Level of Government
Australian Early Development Census (AEDC)	National
Pharmaceutical Benefits Scheme (PBS)	National
Personal Income Tax (PIT) – ATO	National
Child Care Subsidy (CCS)/Child Care Benefit (CCB)	National
Community Health Minimum Dataset (CHMDS) Home and Community Care (HACC)	National
Data Over Multiple Individual Occurrences (DOMINO)	National
Disability Services National Minimum Dataset (DS NMDS) and Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS)	National
Higher Education Information Management System (HEIMS)	National
HILDA	National
Medicare Benefits Scheme (MBS)	National
Medicare Consumer Directory (MCD)	National
NSW National Disability Insurance Scheme (NDIS)	State
Mental health Community Services (MHCSS)	State
NAPLAN data	National
National Death Index (NDI)	National
National Hospital Morbidity Database (NHMD)	National
National non-admitted patient emergency department care database (NNAPEDCD)	National
Nationally Consistent Collection of Data on School Students with Disability (NCCD)	National
NSW Admitted Patient Data Collection (APDC)	State
NSW ChildStory	State
NSW Birth Registration Data Collection	State
NSW Child Protection	State
NSW community preschool census data	State
NSW Education disability	State
NSW Emergency Department Data Collection (EDDC)	State
NSW Government Preschools and Early Intervention Census	State
NSW Out of home care (OOHC)	State
NSW Perinatal Data Collection (PDC)	State
NSW Police Victims' records	State
NSW Preschool Disability Support Program (PDSP) – administered by Northcott NSW Disability and Inclusion Program (DIP) - Higher Learning Support Needs (HLSN) NSW Best Start	State
NSW Re-offending Database (ROD)	State
NSW school enrolment	State
NSW Social housing data	State
Public Housing and State Owned and Managed Indigenous Housing (PH & SOMIH) Data Set	National

Dataset	Level of Government
SA School Enrolment Census	State
SA Certificate of Education	State
Survey of Disability, Ageing and Caring	National
Specialist Homelessness Services Collection (SHSC)	National
Suspension data	State
Attendance data	State
Victorian Admitted Episode Database (VAED)	State
Victorian Emergency Minimum Dataset (VEMD)	State
Victorian Integrated Data Resource (IDR), derivations and tabulations Clinical public mental health services (CMI/ODS)	State
Victorian Integrated Non-Admitted Health (VINAH)	State
Victorian Linkage Map (VLM 1906)	State
Vocational Education and Training (VET)	State

Appendix 4 - The disability sector in Australia

As with all states in Australia, in NSW there are two major social insurance systems which provide most of the funding of services for the treatment, rehabilitation and care for a person with a disability. These are:

- National Disability Insurance Scheme and funding through the National Disability Agreement (NDA) (the latter will progressively transition to the NDIS). Both the NDIS and NDA are Commonwealth government system.
- National Injury Insurance Scheme organisations (NIIS). These state government systems are funded and operated by the state under state legislation. In NSW the funding schemes for the NIIS is Insurance and Care NSW (icare). This organisation incorporates several schemes. They are:
    - Lifetime Care and Support Authority for people catastrophically Injured in a motor vehicle crash (e.g., spinal cord injury, severe brain injury or burns)
    - Workers Care (a part of the Workers compensation Scheme for people who are severely injured with lifelong health conditions as a result of a workplace injury or disease). This section operates within the Lifetime Care and Support framework.
    - Dust Diseases Care for people who have sustained dust diseases through work e.g., Asbestosis, silicosis
    - Treasury Managed Fund – for government agency workers injured
    - Sporting injuries
    - Volunteering injuries

The services both these systems fund is separate and in addition to the mainstream health and care services provided via the Commonwealth and State Departments of Health. The NDIS and state NIIS systems fund treatment rehabilitation and care for people with a disability, provided they meet eligibility criteria and the request for services is determined to be reasonable and necessary (although the determination of what is reasonable and necessary often varies between systems). Similarly, the standards for service providers varies between these systems.

For example, case management in the NIIS is generally performed by people qualified as a health or social welfare professional, and provider lists involve rigorous pre-approval systems on quality and standards.

Mapping markets

People with disability, the disability service sector and governments are rightly concerned about disability services and the disability service market. There have been numerous reviews, enquiries, surveys, research and reports on the Australian disability services and market. Recurring themes arising from these reports include:

- The risks, instability and uncertainty for providers [41-44].
- The confusion often felt by participants and providers regarding the implementation of plans and access to services arising from a lack of information, support to implement plans and ambiguity of roles [45, 46]
- Emerging tensions arising from rights-based approaches, with the expectations and demands of being a consumer, negotiating and understanding systems to make decisions, enact choice and control, while operating in a complex imperfect system with limited information on services and gaps in the market [40, 46-48]
- The significant gaps in services, service capacity and skills of workers [42, 43, 49-53]
- Workforce issues in particular sourcing skilled staff and stressors on existing workforce [41, 46, 49, 50].

In 2016 the NDIA released the Market Approach (A statement of opportunity and intent) to communicate with the market as a market steward for monitoring, facilitating and commissioning e.g. direct sourcing of supports or preferred provider arrangements [43]. The NDIA and NDIS have since published documents and strategy information for the disability service market on an enablement framework and key issues such as rural and remote [42, 54].

A significant body of work and commentary has evolved, even with currently limited information on disability services and providers, and in the absence of granular information on the characteristics of disability services. The most ground-breaking of this – from a mapping perspective – is covered later in this report, under the case study on Functional Network Analysis.