

Features of Intellectual Disability Information System: A Comparative Study

Mozhgan Karimi¹, Farkhondeh Asadi², Hamid Moghaddasi^{2*} and Reza Rabiei²

¹Mozhgan Karimi, student in Health Information Management

²Department of Health Information Technology and Management, School of Allied Medical Sciences, Shahid Beheshti University of Medical Sciences, Tehran, Iran

Corresponding author

Hamid Moghaddasi, Associate Professor of Health Information Management & Medical Informatics, School of Allied Medical Sciences, Shahid Beheshti University of Medical Sciences, Darband St, Qods Square, Shariati St, Tehran, Iran, Tel: +982121-22747373; E-mail: Moghaddasi@sbmu.ac.ir

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Abstract

The aim of this paper is to review the literature related to intellectual disability information systems in the United States, England and Southern Ireland. Electronic databases were used to collate data using key terms such as intellectual disability, service providers, integrated service delivery, organizational structures and features of intellectual disability information system; exchanged data among service providers. This review of the literature presents features of intellectual disability information systems in studied developed countries. It highlights importance of applying integrated and collaborative approaches in providing services as well as exchanged information among the service providers. The study helps to identify what is needed to improve intellectual disability information systems in order to promote appropriate and more effective service management.

Keywords: Intellectual Disability, Information System, Integrated Service, Organizational Structure, System Feature

Background

Individuals with intellectual disability (ID) will require assistance and lifelong support at varying levels based on individual needs, age, health, lifestyle preferences and living conditions [1]. Persons with ID are in need of specialized, integrated and coordinated services which are provided by service providers within the health, education, and social welfare divisions [2]. Therefore, it is essential to develop appropriate strategies for the purpose of improving services offered to people with ID [3].

The success and effectiveness of service delivery system is indebted by proper recognition of Intellectually disabled people's various needs [4]. Integrated services delivery through coordinated service provider network is a useful approach for providing supports to persons with ID regarding their diverse needs [5-8].

It is obvious that provision of integrated and coordinated services require multi-agency communication and information exchange [5]. Information Sharing creates a coordinated network of multiple service providers which includes advantages such as alignment of service providing, access to essential information and improving service management [9,10].

Establishing ID information system links the service provider organizations [11] and facilitates exchange of information between different care settings as well as providing integrated and coordinated services [5]. Intellectual disability Information system is considered as comprehensive source to meet the information needs of service providers [8]. This system also helps targeted management of the

services, the planning of current and future services coordinately, timely referral for receiving services according to the individual's needs and preventing duplication [4,5,12].

In many developed countries, through usage of information systems, measures have been taken to manage intellectually disability services utilizing coordinated approach of service delivery. This solution facilitate decision making, planning, budget allocation, efficient service management and early identification of the individuals with ID using accurate and comprehensive data sets [13-16].

Awareness of structures and characteristics of intellectual disability information system, in developed countries, can pave the way for promotion of purposeful management ID services and improve planning of intellectual disability information system in other countries, including Iran. These are all in line with importance of strengthening inter-agency communication and coordination of service provision in domain of teaching and education, prevention, Health care, rehabilitation [17].

Aim

This study was conducted to investigate the characteristics of the information system of intellectual disability in developed countries such as the United States, England and Southern Ireland.

Method

This is a comparative review study. Literature from the period 2001–2017 was searched, with only works in English language included. Databases used were PubMed, Science direct, Google Scholar, CINAHL as well as review of government websites were also undertaken to identify wider relevant literature. Search terms included 'service providers', 'integrated service', 'organizational

structures', 'features of information system' and 'exchanged data among service providers', and these were paired using Boolean terms along with the terms 'intellectual disability', 'learning disability', 'developmental disability'. The studies' inclusion criteria include Referring to issue of organizational structures and features of intellectual disability information system, determining of exchanged data among service providers in developed countries like the United States, England and Southern Ireland. The reasons for choosing the countries under study was to be developed and to have the highest levels of activity, reports and records related to the management of intellectual disability services through use of information systems. One hundred and five studies were retrieved and examined after searching. Studies in which key components such as elements and characteristics of the intellectual disability information system, organizational structure, and datasets were not mentioned, as well as duplicate studies and articles published before 2001 or published in non-English languages, were excluded. Finally, these were reduced by 56 studies meeting the desired criteria and used in the result section.

Results

In the present study the intellectual disability information systems in the United States, England and Southern Ireland was investigated. Results of this review are summarized according to organizational structure as well as exchanged data among service providers (Table 1) and characteristics of information system in selected countries (Table 2).

The organizational structure of intellectual disability information system and exchanged data among service providers in selected countries

In The United States, the department of developmental services (DDS) manages, supervises and funds ID service system. DDS is one of the departments of Health and Human services (HHS) in the United States. Other departments of HHS like the department of social services (DSS), the department of health care services (DHCS), mental health service division (MHSD), department of public health (DPH) and the department of rehabilitation (DOR) play significant roles in the managing ID service provision. Intellectual disability service system is the product of the collaboration of HHS with department of education (DOE) and department of labor and workforce development (LWD) [18-20].

DDS contracts with non-profit agencies called regional centers (RCs), through which most of treatments and services are provided to children and adults with intellectual disability. RCs as the only entry point are responsible for screening, assessment and diagnosis, service planning, providing or coordinating services for individuals with intellectual disability. The planning team in regional centers determines the appropriate services for each person after necessary assessments. Once eligibility determined, a case manager or service coordinator is assigned to help develop a plan for services. Then, Case manager communicate available services and assist clients with access [18,19].

The education system is the major provider of services to students with intellectual disability in the United States. Schools are required to identify students with special educational needs and provide free services according to the needs of each student. Department of rehabilitation provides vocational rehabilitation services to the individuals with intellectual disability. DOR fundamental

responsibilities includes counseling, interview training , vocational training, job search , employment and job maintenance as well as learning independent life skills [21-23].

Essential functions of Department of social services supports clients by providing cash assistance, help livelihood and enhanced food and nutrition budget, adoption, in -Home support services, tracking of abuse and neglect clients in serving organizations [24]. The department of public health works to protect the safety, health and wellbeing of clients with intellectual disability and ensures the provision of high quality health care services in hospitals and nursing facilities [25]. The department of health care services also is responsible for the management of health care services' plans including Medicaid to fund care services for intellectual disability [26]. (Table 1)

In England, Ministry of health is responsible for decision making about services offered to individuals with intellectual disability. England's clinical commissioning groups (CCGs) and national health services (NHS) are also responsible for disabled people health care needs including Health Check. Local authorities in England are committed to provide social care services and are financially supplied by ministry of housing communities and local government (MHCLG) [27, 28]. In England, the department of work and pension (DWP) is responsible for welfare policy making and disability benefits [29].

Referring to local authorities and application for services and assessment is the first step to receive intellectual disability services in England [30]. Following evaluation and eligibility determination, plan of service will be developed. For each eligible person service coordinator is appointed for Case managing, coordinating service provider organizations and monitoring services according to personal service plan [30-32].

Local authorities must ensure that schools are able to appropriate provision of needed service to students with intellectual disability. Schools are responsible to refer children with special educational needs local authorities too [33, 34]. In England, the service providers are required to participate cooperatively inservice provision for persons with intellectual disability using integrated approach and exchange information together [31-33].

Health and social care Information center (HSCIS) or NHS digital under the supervision of England's ministry of health is responsible for collecting of intellectual disabled people information from information systems and databases of service providers. This information is used for national planning, quality monitoring and developing national reports [35-37]. (Table 1)

In Southern Ireland, the ministry of health is responsible for macro policies in health and social care services including intellectual disability services [38-41].

Health Services Executives (HSE) is responsible for financing, providing a broad range of social services and health care for individuals with intellectual disability. Intellectual disability services are directly provided by health service executives or volunteer organizations with financial supplement by HSE [40]. Department of employment affairs and social protection (DEASP) provides employment support and disability benefits in Southern Ireland.

Interco service center under DEASP's supervision is the only point of contact to receive employment guidance and job counseling for referred individuals with ID [42].

Department of education and skills (DES) and national council for special education (NCSE) are responsible for offering services and allocating resources to students with especial educational needs in Southern Ireland. NCSE provides the students with services through a network of Special educational needs organizers (SENOs) locally. SENOs as representative of NCSE in cooperation with HSE is committed to integrate health service provision and education of special needs students. According to law In Southern Ireland, all schools are responsible to identify special educational needs of students and help to meet these needs [43, 44].

Local health office (LHO) is the entrance point for receiving social and health care services offered by health service executives in Ireland [45]. Public health nurses and GPs identify adults with intellectual disability and children with delayed developments and

refer them to local health office to receive services [46].

In accordance with the Disability Act (2005) in Ireland, the first step towards receiving ID services is to refer to local assessment officer in the LHO and application for services. After needs assessment, service statement is developed for each person according to information confidentiality standards of health and quality authority (HIQA) [40, 47]. HIQA also supervises quality standards and service safety in Ireland [48]. Case manager (Liaison Officer) is responsible for directing; coordinating and monitoring services and scope of services which not fully covered by health service executives, there will be waiting lists for disabled people [45, 47, 49]. (Table 1)

Results revealed that in all reviewed countries core data which exchanged among service providers database include Demographic data, administrative and financial, client's needed services and provided services, Service Providers and Service results [16, 18, 22, 35, 36, 45, 46].

Table 1: Organizational structure of intellectual disability information system and exchanged data among service providers in selected countries

Country under study	Intellectual disability service managing organization	Related databases	exchanged Data
The United States	Department of Health and Human Services (department of developmental services)	Data base of Department of rehabilitation Data base of Department of public health Data base of Department of health care services Data base of Department of Education Data base of Regional centers Data base of Labor and workforce	Demographic data , administrative and financial, client's required services and provided services (Clinical , Non-clinical) , Service Providers , Service result
England	Ministry of Health	Data base of National health services (NHS) Data base of Clinical Commissioning groups(CCGs) Data base of local authorities (LA) Data base of Department of work and pension Data base of department for education Data base of NHS Digital	Demographic data , administrative and financial, client's required services and provided services (Clinical , Non-clinical) , Service Providers , Service result
Southern Ireland	Ministry of Health	Data base of Health service executives(HSE) Data base of Department for employment affairs and social protection(DEASP) Data base of Department of education and skills(DES) Data base of Local health office(LHO) Data base of National intellectual disability database(NIDD)	Demographic data , administrative and financial, client's required services and provided services (Clinical , Non-clinical) , Service Providers , Service result

The characteristics of Intellectual disability information systems in selected countries

In The United States, information system of the department of developmental services is a secure web-based system that is used to information storing, supporting, coordinating and monitoring services offered to individuals with intellectual disability. DDS information system consists of several components include following:

- a) The client master file (CMF): contains the client unique identifier, demographic information, age, race, language, disability details, and type of residence of clients.
- b) Client development Evaluation report (CDER): includes assessment and diagnosis information and performance evaluation

for individuals over 3 years old to develop person-centered individual program planning [50, 51].

- c) The early start report (ESR): includes evaluation information of delayed development for children less than 3 years old in order to receive early intervention.
- d) Purchase of service (POS): includes service type, clients, service provider organization and the number of needed services.
- e) Service providers profile (SPP): includes service provider unique identifier, place of service, organization address and under contract regional center.
- f) Special incident report (SIR): includes the report of any undesirable event by service providers to regional center (Such as missing people, abuse or maltreatment, suspected neglect, serious injury and accident, unplanned hospitalization, medication occurrence reporting, victim of crime, un expected death) for the purpose of quality monitoring and tracking of service consequences [13, 52].

Regional centers use a system, which called e-billing, to manage the electronic operation and reimbursement of the providers' services. Receiving and sending the information in e-billing system is encrypted among IT systems [50]. The information is collected for each client and is reported monthly to the department of developmental services by the Regional Centers to provide a performance report and financing [53, 55].

In England, Local information system (LIS) is a powerful and secure platform that is developed by local authorities. The LIS aims at providing data collection, storage and data analysis as well as exchange, tracking and update of information, services payment, reporting and providing of accurate local statistics.

Local authorities maintain client's personal information in LIS securely and in compliance with security measures. Local information system includes demographic information profiles, individualized service-planning information, directory of available services, service provider agencies, early intervention services for children, adults' social services and waiting list. Local information system also has a directory of services for children with special education need and disability. This section contains EHCP plan information with Health and social care, education housing, employment and leisure opportunities [56-59].

Using NHS number, as a unique identifier, is important strategy for information exchange and integrating service provision to clients. Local authorities use NHS number to link health and social care information as well as providing of collaborative and integrating services [60]. In this way, information is exchanged between IT systems of service providers in the social and health care services while maintaining the confidentiality and privacy. It also enables service providers to identify and report any case of neglect, abuse, harassment, negligence happening for individuals with intellectually disability in order to quality monitoring [61].

Data, related to health check of persons diagnosed with intellectual disability, is extracted automatically from general physician's clinical information systems using general practice extraction service (GPES)

and is submitted to commissioners for supervision, approval and planning [62]. GPs are required to refer the individuals identified as intellectually disabled to local authorities for screening and service planning [63].

Hospital episode statistics (HES) is used to collect clinical data of patient with intellectual disability during hospitalization episodes as a part of commissioning data set and then is sent to NHS digital for processing [64]. Data set related to hospitalization of clients diagnosed with intellectual disability and mental disorders known as assuring transformation (AT), is sent to NHS digital by clinical commissioners through a system known as clinical audit platform as an online secure system for entering and sending data [65]. Data set of national adult social care intelligence service (NASCIS) is a collection of data, analyzing and reporting tool developed as a current national source of social care services by HSCIS. Local authorities are required to collect NASCIS data and send it to NHS digital [66, 67].

In southern Ireland, National intellectual disability database (NIDD) is a national information system for intellectually disabled people. NIDD database is owned by the Ministry of Health. The NIDD aims to provide accurate and comprehensive information for decision-making, planning services, prioritizing need for services and help to identify clients. Other main goals of NIDD are also determination of future required services and monitoring current services such as daily services, residential, multidisciplinary support service and early intervention [16].

Information is continuously collected on a daily basis in the NIDD database which contains following sections:

- a) The details of personal information of each client including unique identifier, date of birth, gender, address, level of intellectual disability
- b) Details of current services including type of service, service provider organization, frequency of receiving service
- c) Future required services including type of service, year of service provision, frequency and times of service provision
- d) Administrative information such as assessment and service provision date, LHO responsible for reporting information, service cost and the organization's reimbursement obligation [15, 68].

Each service providers like HSE local health office, school principals and other volunteer organizations, collects information of individuals with intellectual disability. Service providers after completing the standard Form of NIDD send it to the health service executives. Then HSE send aggregated information to health research board (HRB) for analyzing in national level. Health research board, under the supervision of health ministry, extracts reports from NIDD annually. These reports will be published with respect to the principles of confidentiality by HRB. Obtained reports provide comprehensive service planning, service quality monitoring of demographic trends and effective coordination for intellectual disability services in the regional and national levels [15,68] (Table2).

Table 2: Characteristics of intellectual disability Information System in Studied Countries

Country under study The characteristics of the information system	United States	England	South Ireland
Database system with centralized architecture	—	—	√
Database system with distributed architecture	√	√	—
unique identifier for data exchange	√	√	√
index of client’s profile	√	√	√
service providers index	√	√	√
client’s continuous information storing	√	√	√
client’s Individual-centered planning of service	√	√	√
The possibility of following and tracking services	√	√	√
Service Case Management	√	√	√
Integrated and coordinated approach in service provision	√	√	√
Inter-organizational Information Exchange	√	√	√
Client Identification and screening	√	√	√
Provide early intervention	√	√	√
Prioritizing the need for services and managing waiting lists	—	√	√
Adverse Event management and tracking outcomes	√	√	—
Quality monitoring	√	√	√
The possibility to reporting	√	√	√
Managing reimbursement operations	√	√	√
Compliance with confidentiality principle in information exchange	√	√	√

Discussion

This study was conducted to comparatively investigate the characteristics of the intellectually disability information system in the United States, England and southern Ireland. The results of this study indicate that in all three studied countries, Ministry of Health is responsible for decision making about intellectually disability services [19,27, 40, 41].

Intellectual disability system is the product of cooperation among different departments and organizations in health care, social, education and disability services in selected countries [19, 35, 40]. Mentioned agencies provide integrated and collaborative services in order to meet the multiple needs of clients. In hence, Service providers are requiring to sharing information to coordinate services and supports [35,40,69].

The results of the review revealed that, usage of information system is a factor to strengthen communications and information exchange in accordance with the confidentiality standards as well as provision of integrated services [52,57,68, 70]. Therefore, it can be concluded that effective management of intellectual disability services requires sharing of information through an efficient information system [8, 9]. Intellectual disability information System links service providers in different organizations and makes it possible to exchange information and provide integrated services through coordinating of available data sources [5, 11, 71].

Providing a coordinated approach to service delivery, in addition to focusing on complex and widespread needs of clients, and the application of standard treatment protocols, will prevent conflicts of service or responsibility of organizations, waste of resources and ensuring long-term and continuous support for individuals with

intellectual disability [15,69,72].

Min Wu (2005) in a study titled “design of an integrated system for children with intellectual and developmental disabilities” describes intellectual disability service delivery system as a complicated system including diverse service provider agencies. Therefore, coordinating service provision entails usage of integrated information system with the possibility of data exchange. The results of the above study showed using information system follows some benefits such as enhancement data exchange and management, early intervention services improvement and the possibility of tracing ID services [73].

The results of the present study showed that in the studied countries, information exchanged by service providing agencies include demographic information, assessment and diagnostic information, clinical and non-clinical services, services results and financial and administrative information. The above information is usually collected by each service providing organization in accordance with the individual planning document and case manager is required to track and monitor the services provided by the agencies [22, 31, 34, 40, 47].

Dahmet al (2017), in a study on describing the information infrastructures for intellectually disabled people residing in supported accommodation, emphasizes that the effectiveness of the services and information infrastructure can be improved through integrating information sources with focusing on possibility of exchange clients ‘information among service providers [74].

The present review showed that in Southern Ireland, national intellectual disability database (NIDD) System is designed by centralized architecture [15]. While in The United States and

England its architecture is distributed and in a way that data is maintained locally and it is possible to access and share information with service providers data bases if necessary [28,35, 36, 52, 75]. For example, in England, despite using numerous information systems in various social and health care divisions, secure and protected sharing project known as “child protection information sharing(CP-IS)” is implemented to links different information systems in service providing organizations. Therefore, the information can be exchanged securely in social and health care sectors among service providers. CP-IS with the possibility of immediate access to needed information enables each expert and service provider to collaborate and cooperate closely [61].

In a study entitled “The information system on disability” conducted to fill the information gap and organized processing information using coordinated information resources, Baldassare, et al. (2008), revealed that the intellectual disability information system include a widespread spectrum of dimensions of health services, social services, education, employment, family, incidents, safety, Life and social inclusion, service provider organization, financial resources and the welfare facilities according to sex, age and level of intellectual disability. Service provider organizations are responsible to collect the information relates indicators and complete data resources in order to meet their goals. The results of the present study are in line with the findings of above study [71].

The findings of this study showed that the management of waiting lists to prioritize service needs is not considered as a component of the intellectual disability information system in the United States Because Home and community-based support services (HCBS Waiver) for individuals with ID is under supervision of Medicaid as a substitution for institutions whereby the number of people in need of services in institutions and other settlements has reduced [76,77]. This investigation showed that adverse event management and undesirable outcomes tracking are not defined as a component in the NIDD database in Ireland. This web-based information system lacks diagnostic information; therefore, it could support planning, prioritizing, budgeting and managing of the intellectual disability services rather than accomplishing medical or epidemiological purposes [78].

According to the results of this study, an intellectual disability information system has following characteristics. It improves screening, early diagnosis and intervention, better understanding of needs and ensure the desired outcomes [72,79, 80]. Other features of the intellectual disability information system include Monitoring and tracking services, managing waiting lists, case management (targeted services for eligible clients, multidisciplinary service delivery, Services evaluation and identify deficiencies [69,81-83]. Provision of client’s profile index, service provider index, Information storage, personalized service planning, integration and coordination of services, information exchange, adverse event management, reporting and reimbursement management [15, 50-52, 57, 59, 68].

Conclusion

The effectiveness of the infrastructures of intellectual disability information systems can be improved by integrating the existing information sources and supporting data exchange among various service providing organizations. In this regard, awareness of the structure and characteristics of the intellectual disability information

system in developed countries as well as the use of experiences from leading countries can pave the way for promoting the design of intellectual disability information system and enhancing intellectual disability service management in Iran.

References

1. Service Framework to Improve the Health Care of People with Intellectual Disability (2012) NSW Ministry of Health 6. <https://www.health.nsw.gov.au/disability/Publications/health-care-of-people-with-ID.pdf>.
2. Werner S (2012) Individuals with Intellectual Disabilities: A Review of the Literature on Decision-Making since the Convention on the Rights of People with Disabilities (CRPD), *Public Health Reviews* 34: 2. <https://publichealthreviews.biomedcentral.com/track/pdf/10.1007/BF03391682>.
3. Nejati V, Zabihzadeh A, Maleki G (2012) Comparing Quality of Life of Severely Mental Retarded in Home and Residential Center’. *Iranian Journal of Exceptional Children* 11: 353-361.
4. Behpazhoh A, Karimi H, Mahmoudi H (2015) pre-professional need assessment of intellectually disabled students. *Exceptional education* 132.
5. Goldwater J, Yuhasz L (2011) Consideration for clinical integration’ *Truven health analytic*. <https://www.Truvenhealth.com>.
6. Jansen D, Krol B, Groothoff J, Post D (2006) Integrated cares for intellectual disability multiple sclerosis. *Journal of integrated care* 12. <http://www.ijic.org>.
7. Kaehne A (2012) Do integrated Health and social care services deliver better care for children with intellectual disabilities. *Journal of integrated care* 12: e149. <http://www.ijic.org>.
8. Lind A, Archibald N (2011) structuring new service delivery models for individuals with intellectual and developmental disabilities. *Center for health care strategies Inc*. www.chcs.org.
9. Bonardi A, Lauer E, Mitra M, Bershadsky J, Taub S et al. (2011) Expanding surveillance of adults with intellectual disability in the united states. *Center for Developmental Disabilities Evaluation and Research (CDDER)*. <https://www.umassmed.edu/>.
10. Wodchis PW, Dixon A, Anderson MG (2015) Continuing efforts to integrate care can benefit from cross-jurisdictional comparisons. *International Journal of Integrated Care* 15: e012. <https://www.ncbi.nlm.nih.gov/pmc/articles>.
11. Alabama Division of Developmental Disabilities (2013) Alabama division of intellectual disabilities information system (ADIDIS). <http://www.mh.alabama.gov/>.
12. Shariati N, Davarmanesh A (2001) the Effects of Child Mental Disability on Family. *Tehran Welfare Organization*.
13. California Health and Human Services Agency (2006) Fund data report <https://www2.ed.gov/>.
14. Data for Neighborhoods and Regeneration Data 4nr (2012) Local information system. <http://www.data4nr.net/>.
15. Hourigan S, Fanagan S, Kelly C (2017) HRB Statistics Series 37 Annual Report for National Intellectual Disability Database Committee, *Health Research Board*. <https://www.hrb.ie>.
16. Kelly F, Kelly C, Donohoe AO (2012) Report for NIDD Committee Annual, *Health Research Board*. <http://www.hrb.ie/>.
17. Iran Behzisti organization (2015) Inter-organizational cooperation memorandum between the Exceptional Education Organization and the Behzisti Organization.
18. Department of Developmental Services (2016) <http://www>.

- dds.ca.gov/.
19. California's Developmental Disabilities Service System (2013) Fundamentals brief disability system. The Scan Foundation Organization. <http://www.thescanfoundation.org/sites/default/files/ltc>.
 20. Labor & Workforce Development Agency (2018) <http://www.labor.ca.gov/>.
 21. San Diego Regional Center (2017) <http://sdrcc.org/>.
 22. Tri-Counties Regional Center (2017) <http://www.tri-counties.org/>.
 23. Valley Mountain Regional Center (2017) How to apply for services <https://www.vmmc.net>.
 24. California Department of Social Services (2017) <http://www.cdss.ca.gov/>.
 25. California Department of Public Health (2017) <https://www.cdph.ca.gov/>.
 26. California Department of Health Care Services (2017) <http://www.dhcs.ca.gov/>.
 27. National Audit Office -DoH (2017) Local support for people with a learning disability. Report for Department of health. <https://www.nao.org.uk/wp-content/>.
 28. Committee of Public Accounts (2017) Local support for people with a learning disability. Report for House of Commons <https://publications.parliament.uk/>.
 29. United Kingdom public sector information Gov UK (2017) <https://www.gov.uk/>.
 30. How to get care and support (2017) Factsheet for Age UK <https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/>.
 31. England NHS (2016) Learning disabilities care children young people SEND <https://www.england.nhs.uk/>.
 32. England NHS, Local Government Association and Directors of Adult Social Services (2015) Supporting people with a learning disability and/or autism who display behavior that challenges, including those with a mental health condition, Report for TCPs. <https://www.england.nhs.uk>.
 33. England NHS, Local Government Association (2017) Developing support and services for children and young people with a learning disability, autism or both. Guideline for NHS &LGA. <https://www.england.nhs.uk/>.
 34. Health Conditions in Schools Alliance (2014) Caring for children with medical conditions in school—legal information. <http://medicalconditionsatschool.org.uk/documents/Legal-Situation-in-Schools.pdf>.
 35. Hatton C, Emerson E, Glover G, Robertson J (2013) people with learning disabilities in England. Public health England. www.improvinghealthandlives.org.uk.
 36. NHS Digital UK. (2017) <https://digital.nhs.uk/data-and-information>.
 37. Turner S, Robinson C (2010) Health Checks for People with Learning Disabilities: Implication and actions for commissioners IHAL. <http://www.improvinghealthandlives.org.uk/>.
 38. Government Structure in Ireland (2010) Center for ageing research and development. Resource document. <http://www.cardi.ie/userfile>.
 39. Ireland Department of Health (2017) <http://health.gov.ie/about-us>.
 40. Ireland Health service executive's services list disability (2017) <https://www.hse.ie/eng/>.
 41. Ireland Who Does What (2016) <https://whodoeswhat.gov.ie/departments/health/>.
 42. Department of Employment Affairs and Social Protection (2017) <http://www.welfare.ie/en/Pages/Intreo.aspx>.
 43. European agency for special needs and inclusive education country information Ireland (2016) <https://www.european-agency.org/>.
 44. National council for special education Post school education and training information on options for adults and school leavers with disabilities (2014) Guideline for NCSE. <http://ncse.ie/wp-content/>.
 45. Ireland Health service executives LHO service list (2017) <http://www.hse.ie/eng/>.
 46. Guide to entitlements for people with disabilities (2017) Citizens Information Board Guideline. <http://www.citizensinformationboard.ie/downloads/guides>.
 47. Ireland Citizens Information Community Health Care Services (2013) <http://www.citizensinformation.ie>.
 48. National Hygiene Services Monitoring Assessment Report (2010) Royal Victoria Eye and Ear Hospital, Dublin. <https://www.hiqa.ie>.
 49. Ireland Home Instead Community Care (2013) <https://www.homeinstead.ie/docs/default-source/default-documentlibrary/Community-Care-Mar.pdf>.
 50. Client Development Evaluation Report (2016) Department of Developmental Services. http://www.dds.ca.gov/CDER/docs/CDERMannual_Overview.pdf.
 51. Client Master File (2016) Department of Developmental Services. <http://www.dds.ca.gov/FactsStats/>.
 52. Anderson M, Bischoff U, Acumen WJ (2007) Using Data to Manage Risks: Recent Efforts in California. <http://www.reinventingquality.org/>.
 53. Alta Regional Center Accounting e-billing current service providers (2017) <http://www.altaregional.org/>.
 54. Association of regional center agencies regional center caseload ratios (2015) <http://www.chhs.ca.gov/>.
 55. Resources support San Diego Regional Center (2016) <http://sdrcc.org/>.
 56. Local information system (2017) Barnsley council. <https://www.barnsley.gov.uk>.
 57. Foley P, Alfonso X, Wiseman I (2007) Local Information Systems: A review of their role, characteristics and benefits. Department for Communities and Local Government. <http://webarchive.nationalarchives.gov.uk>.
 58. LIS Fluent technology ltd (2017) <http://www.localinformationsystems.co.uk/home>.
 59. Local Authorities and disabled adaptations (2016) Focus report for local government Ombudsman <https://www.lgo.org.uk>.
 60. Sharing Data and Information to support Education Health and Care Plans (2014) Council for disabled children information Sharing. Guidance for practitioners and managers <https://councilfordisabledchildren.org.uk/>.
 61. The Child Protection-Information Sharing project (CP-IS) (2017) NHS Digital. <https://digital.nhs.uk/about-nhs-digital/>.
 62. Technical requirement for GMS contract changes (2017)

- NHS England, British Medical Association (BMA) and NHS Employers Org. <http://www.nhsemployers.org>.
63. Emerson E, Copeland A, Golver G (2016) The Uptake of health checks for Adults with learning disabilities <https://www.improvinghealthandlives.org.uk/>.
 64. Hospital episode statistics (2017) <https://digital.nhs.uk/data-and-information/>.
 65. Assuring transformation (2017) <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/>.
 66. Information and guidance on the Referrals (2012) Assessments and Packages of Care (RAP) collection for the collection period 1st. <http://www.hscic.gov.uk/media/>.
 67. National Adult Social Care Intelligence Service (2015) <https://nascis.hscic.gov.uk/Portal/About.aspx>.
 68. Kelly C (2014) HRB Statistics Series. 28 Annual Reports for National Intellectual Disability Database Committee, Health Research, Dublin Ireland <http://www.hrb.ie/u>.
 69. Palmer B, Miles J (2014) Cooperative planning handbook for youth with developmental disabilities. Colorado DOE, Colorado DHC policy financing and Division for intellectual and developmental disabilities.
 70. Hogan B, Bazinsky K, Waldman B (2014) Approaches to the Integration of Services for Individuals with Intellectual and Other Developmental Disabilities. State Health and Value Strategies program, Robert Wood Johnson Foundation.
 71. Baldassare G, Battisti A, Busalo DE, Palma DE, Solipaca A (2008) The Italian information system on disability. *Journal of public health* 5: 112-116.
 72. World Health Organization (2010) Better health, Better lives: children and young people with intellectual disabilities and their families, identifying the needs of each child and young person. WHO regional office for Europe. http://euro.who.int/intellectual_disabilities.
 73. Wu M, Rhyner P (2005) Design of an integrated system for Milwaukee children with developmental disabilities. In: AMIA Symposium Proceedings 2005: 1156. <https://www.researchgate.net/>.
 74. Dahm MR, Georgiou A, Balandin S, Hill S, Hemsley B (2017) Health Information Infrastructure for People with Intellectual and Developmental Disabilities (I/DD) Living in Supported Accommodation: Communication, Co-Ordination and Integration of Health Information. <https://preview.ncbi.nlm.nih.gov/pubmed/>.
 75. Magdalena IN, Moise LM (2015) Centralized vs. Distributed Databases Case Study. *Journal of Economic Studies* 1.
 76. Medicaid Waiver organization, California Medicaid Waiver Disability Services & Waivers (2017) <http://medicaidwaiver.org/state/california.html>.
 77. Department of Developmental Services Home and Communities Based Services HCBS (2016) <http://www.dds.ca.gov/>.
 78. Barron S, Kelly C (2006) Report for National Intellectual Disability Database Committee, Health Research Board, Dublin Ireland. http://www.hrb.ie/fileadmin/publications_files/NIDD2006.pdf.
 79. Koegel KL, Koegel LR, Ashbaugh K, Bradshaw J (2014) the importance of early identification and intervention for children with or at risk for autism spectrum disorders. *Journal of speech-language pathology* 16: 50-56.
 80. Leitner PR, Chenoweth B, Johnson J, Lenroot R, O'Connor L, et al. (2014) Metro-Regional Intellectual Disability Network (MRID.net) A Statewide Collaborative Multidisciplinary Care Model. *World Congress on Integrated Care* 14. <http://www.ijic.org/>.
 81. Crawford LJ (2013) Computer support and the clinical process: An Automated Behavioral Rehabilitation System for Mentally Retarded Persons. *American Association of Intellectual & Developmental Disabilities*.
 82. About intellectual-disability network (2015) Agency for Clinical Innovation (ACI). <http://www.aci.health.nsw.gov.au>.
 83. Agency for Clinical Innovation (ACI) intellectual disability health network (2016) Context Report and Toolkit for health services of people with intellectual disability. <http://search.proquest.com/open>.

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