



Isle of Man
Government

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Rhyenn Kiarail y Theay

CONSULTATION DRAFT

ADULT LEARNING DISABILITY SERVICE STRATEGY



Executive Summary

This Strategy lays out proposals for the commissioning of services for adults with learning disabilities in the Isle of Man. The Strategy recommends that services should be reorganised to provide more personalised support and care, rather than fit people into existing or pre-purchased services. It focuses on priorities (personalisation, safeguarding, employment, health and housing) which maintain people's 'citizenship', rather than have statutory services replace people's existing support networks. The creation of an effective Learning Disabilities Partnership Board (Learning Disabilities Partnership Board), with working sub-groups that reflect the above priorities, will promote greater involvement, control and choice for people with learning disabilities in the Isle of Man.

This second Five Year Strategy builds on the previous strategy and sets out how people with a learning disability should be included and supported in the community in which they live. Adults with learning disabilities will also have information about services to support their needs, so that they can participate in decision-making relative to their own lives. People will also be able to use local services, wherever possible, and specialist services when they need them. They will have greater opportunities to get a paid job and develop as individuals.

The strategy is divided into sections followed by a series of recommendations which set out how services should be planned, commissioned and delivered in the future. The scope and purpose section of the strategy identifies those people covered by the strategy which is linked to the proposed introduction of Fair Access and Charging (FACS) in the Isle of Man.

Definitions and Values section differentiates between learning disabilities and learning difficulties. It also describes Autism Spectrum Disorder or Autistic Spectrum Conditions (A.S.D/A.S.C).

Involving Service Users and Families/Carers section explores how 'involvement' can be better achieved with the introduction of the Social Services Act and the proposed creation of the Learning Disabilities Partnership Board and its associated sub-groups. This is based on the four priorities contained in Valuing People Now. The proposed Learning Disabilities Partnership Board will need leadership and focus to be effective.

Review of the Previous Strategy section describes what progress has been made since 2007 and what work is in progress or has not been achieved.

Prevalence is probably the most interesting section relating to prevalence rates of learning disabilities and A.S.D/A.S.C. in the Isle of Man by extrapolating prevalence data taken from the U.K. and comparing (where possible) with data collected from various departments and services across the Island. This data shows a higher than expected number of pupils identified with severe and profound/multiple learning disabilities in the educational system. The undertaking of this prevalence exercise will better inform the Department of projections of present and future demand. This will help the future planning of services for adults with learning disabilities and A.S.D/A.S.C.

Future Demands/Case for Change sections catalogue the challenges in commissioning future services and the proposed changes in legislation/policy with the emphasis on rebalancing services to meet increasing and changing needs.

Service Areas and Priorities section focuses on the identified four priorities and describes each service area. The employment of adults with learning disabilities is a recognised priority and recommends configuration of services which improve people's skills and the expansion of employment opportunities in conjunction with our partners. The proposed rebalancing of resources will place future emphasis on the development of alternative models of accommodation and support.

The proposed reduction in the proportion of spending on residential care and corresponding increase in funding for alternative models of accommodation and support will increase choice and independence for adults with learning disabilities and A.S.D/A.S.C. in line with the principles contained in Valuing People Now. The improvement of healthcare provision for adults with learning disabilities and A.S.D/A.S.C. remains a priority for future services.

Although much work has been done to address health inequalities in the Isle of Man, more needs to be done regarding monitoring access to primary health care services, the development of various care pathways and the screening of people with Down's Syndrome for dementia.

The personalisation/including everyone priority describes how all eligible groups of people should be involved in planning and designing their own support services. People with assessed learning disabilities, A.S.D/A.S.C., complex needs, challenging behaviours and young people in transition should all be included in the commissioning of their care and support packages. This will require changes to existing resource allocation and commissioning systems. The implementation of the Social Services Act and the proposed introduction of Fair Access to Care Services (FACS) should ensure clear and transparent eligibility criteria for both potential service users and carers.

The key priority of personalisation needs to be balanced with a requirement that people live their lives safely. The proposed establishment of an adults Safeguarding Board with wide representation should help support vulnerable groups of people to keep themselves safe. This proposed Safeguarding Board should monitor implementation of changes in policy/practice and produce and submit annual reports to the proposed Learning Disabilities Partnership Board

Financial Resources section shows that current investment made by the Department of Social Care is approximately £11,685,000, excluding nursing home/health service costs. Over 80% of this entire revenue budget for 2011/12 was invested in on/off Island residential care. This is a very traditional profile of spend and over the next five years the Department of Social Care will need to commission more community support and reduce the proportion of spend on residential care in line with national and international policy drivers. The challenge facing Learning Disability Services on the Isle of Man is to meet increasing demand within allocated resources while moving towards greater personalisation and more preventative services to support people with learning disabilities.

Benefits section outlines that there are likely to be developments relating to broader means testing for services in the future. This process will identify eligible need, determine the associated cost of appropriate care services and apply a financial assessment to determine the level of contribution.

Workforce Development section looks at the training and support of staff in the delivery of personalised services which will be assisted by the formulation and implementation of an Adult Social Care Workforce Strategy.

Measuring Outcomes should be linked to the four priority areas (work, housing, health and personalisation) and should be incorporated into a comprehensive performance and outcomes framework.

Reviewing this Strategy and the accompanying service delivery plan provides the basic framework for strategic planning against which progress can be measured. An interim review of this strategy should take place during 2015 and thereafter before the formulation of the next strategy 2019 - 2024.

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Scope and Purpose

Purpose

This is the second Five Year Strategy (2012-17) for adults with a learning disability who are resident in the Isle of Man. The purpose of a strategy is to outline the 'direction and scope of an organisation over the long term through its' configuration of resources' (1). There are three dimensions to successful strategic application: -

1. Analysis of the organisation's position, demands, costs. (S.W.O.T.)
2. Deciding and selecting the strategic expectations and options which the organisation will meet.
3. Implementing the strategy is often the hardest part. Translating the selected strategy into organisational action.

This Strategy describes the vision, aims and outcomes for the Adult Learning Disability Service on the Isle of Man. It sets out how Adult Services will deliver services for people with a learning disability on the Island, in accordance with the expectations of the 2009 Valuing People Now Strategy (2).

This strategy provides a framework to support the commissioning/provision of services that are both responsive/equitable and sets out the planned actions to achieve specified outcomes for the provision of services. It is important to note that services on the Isle of Man are governed by different legislation than is the case in the U.K. and are, therefore, structured differently.

Scope

The strategy covers the provision of services for adults (over 18 years old) with learning disabilities residing on the Isle of Man who are assessed as being eligible for support. People with learning disabilities over 65 years will continue to receive services through the Adult Social Care Service, in conjunction with Older Peoples Services. It identifies the commissioning intentions based on current information pertaining to identified needs and sets targets to achieve a shift towards services that enhance independence and support

community based provision. It applies to services provided directly by Social Care, the private and Third Sector.

Therefore, this strategy is a formal plan which will: -

- Effect change in the overall configuration of Learning Disability Services to meet the needs of adults with learning disabilities on the Isle of Man.
- Ensure a planned approach to providing/commissioning of services making use of information about demand, unmet needs/service gaps and resources.
- Take account of the impending introduction of fair access and charging for services.
- Set out the direction and structure of future service provision, taking cognisance of the priorities laid out in Valuing People Now: The Delivery Plan 2010 -2011.
- Ensure that services are centred on service user needs which are linked to local target indicators.
- Provide a clear statement of commitment about how stakeholders (users, carers, providers) are involved in the planning and commissioning of services.

References

1.	'Exploring Corporate Strategy' - Johnson, Gerry and Scholes, Kevin (2010)
2.	'Valuing People Now: A New Three-year Strategy for People with Learning Disabilities' (2009) - Department of Health UK

Definitions of Learning Disabilities

Learning Disabilities

The World Health Organisation (1) defines learning disabilities as a 'state of arrested or incomplete development of mind accompanied by significant impairment of intellectual and social functioning'. It is a condition which reduces the ability to learn new things resulting in difficulties with some social tasks such as communication, self care and awareness of health and safety. These impairments are present in childhood and not acquired as a result of an accident or illness in adulthood. In the U.K. learning disabilities are categorised based on IQ test scores as follows: -

- 50-70 - Mild
- 35-50 - Moderate
- 20-35 - Severe
- Less than 20 - Profound

Valuing People, the 2001 White Paper (2) on the health and social care of people with learning disabilities, included the following definition of learning disabilities:-

Learning disability includes the presence of: -

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development.

Adults are considered to have a learning disability if they have been identified as a child within education services as having a Special Educational Need (SEN) associated with moderate, severe or profound/multiple learning difficulty.

Adults with learning disabilities who have been assessed as meeting the threshold for access to adult care services on the Island, as set out in the impending implementation of a 'Fair Access to Care Services', will be eligible for support.

Learning Difficulties

The umbrella term, specific learning difficulties (SpLD), is used to include a range of difficulties (3). These include: -

- Dyslexia - difficulty with words
- Dysgraphia - writing difficulty
- Dyspraxia - motor difficulties
- Dyscalculia - a difficulty performing mathematical calculations
- Attention Deficit Disorder or Attention Deficit Hyperactive Disorder (ADD or ADHD):- concentration difficulties with heightened activity levels and impulsiveness.

Autism Spectrum Disorder or Autistic Spectrum Conditions (A.S.D./A.S.C.)

The idea of Autism as a spectrum disorder, covering a range of ability levels but characterised by a triad of impairments in social, communicative and imaginative development, was introduced by Wing and Gould (4) in 1979. Wing and Gould proposed that Autism Spectrum Disorder (ASD) could be viewed as a life-long developmental disorder where the following triad of impairments are present: -

- Social interaction - impaired, delayed or atypical social development, especially interpersonal development, varying from 'autistic aloofness' to 'active but odd'.
- Language and communication – impaired and/or abnormal, verbal and non-verbal, semantic and pragmatic aspects of language.
- Thought and behaviour – rigidity of thought and behaviour and impoverished social imagination, ritualistic behaviour, reliance on routines, extreme delay or absence of pretend play.

This strategy will encompass people with the following characteristics: -

- Learning Disability (mild, moderate, severe)
- Profound/Intellectual and Multiple Disability
- Challenging Behaviour in addition to a recognised learning disability.
- Autistic Spectrum Disorder (Conditions) linked to a learning disability
- Adults with learning disabilities and additional mental health needs (dual diagnosis)
- Older People with a learning disability

- Family Carers including older Parents and Carers.

References

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| 1. British Institute of Learning Disability Fact Sheet – what is a learning disability? January 2004
www.bild.org.uk |
| 2. Valuing People: A New Strategy for Learning Disability for the 21 st Century. 2001. Department of Health |
| 3. What are Specific Learning Difficulties? www.open.ac.uk/inclusiveteaching/pages/understanding-and-awareness/what-are-specific-learning-difficulties |
| 4. Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. Journal of Autism and Developmental Disorders, 9, 11-29. Wing, L & Gould, J (1979). |

Values and Principles

The values and principles set out in the previous Isle of Man Learning Disability Strategy 2007-2012, 'Living Life To The Full' (1) are as relevant today as they were in 2007. These basic principles stated that people have

- The right to be treated and accepted as citizens.
- The same human value as anyone else.
- The right to be treated with dignity and respect.
- The right to be treated as individuals.
- The right to safety and not to be bullied or abused.
- The right to sexuality and relationships.
- The right to live in and be part of their communities in ordinary homes.
- The right to grow up in families.
- The right to learn with other children.
- The right to be with and enjoy family and friends.
- The right to help and support to develop as individuals in communities and achieve all the above.
- The right to be decision makers in their own lives.

This strategy sets out how services for adults with learning disabilities will be delivered on the Isle of Man, in accordance with the values and principles contained in Valuing People Now Strategy 2009 (2) and Valuing People Now: The Delivery Plan 2010-2011 (3). Valuing People Now strategy states that adults with learning disabilities should have equal human rights to those who do not have disabilities. The four guiding principles are: –

1. **Rights:** People with learning disabilities and their families have the same human rights as everyone else.
2. **Independent Living:** All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.
3. **Control:** This is about being involved in, and in control of, decisions made about their lives. This is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.

4. **Inclusion:** This means people being able to participate in all aspects of community – to work, learn, get about and meet people, be part of social networks and access goods and services with the support to do so.

In recent years, many people with learning disabilities and their families have a greater voice and control over their own lives and the services they use. However, there are still issues around social exclusion, poverty and isolation. The current Valuing People Now Strategy (3) targets a number of areas for immediate action such as; including everyone, personalisation, having a life and people as citizens. The emphasis of this new approach is to uphold the human rights of all people with learning disabilities.

References	
1.	Living life to the full'. P.19-21. Isle of Man Government 'The Isle of Man Learning Disability Strategy 2007 – 2012
2.	Valuing People Now: a new three-year strategy for people with learning disabilities. 'Making it happen for everyone' (2009) HM Government
3.	Valuing People Now: The Delivery Plan 2010-2011. 'Making it happen for everyone' HM Government

Involving Service Users and Families/Carers

Isle of Man Learning Disability Services are committed to the principle of involving people with learning disabilities and carers in the delivery and evaluation of their own care and support. The implementation of successful involvement of people with a learning disability and their carers is identified as a key priority in Valuing People (2001). Valuing People Now (2009) places great emphasis on people with learning disabilities and their carers being involved in decision-making regarding the range, quality and choice of support and care services available in every local area. This includes people with complex needs and those on the autistic spectrum. All carers of people with a learning disability on the Isle of Man will soon be eligible for an assessment of their own needs under new legislation (1).

Although the Isle of Man does not yet have some of the legislation, structures and benefits that exist in the U.K., both the previous strategy and this strategy support and strive to progress the principles contained in Valuing People. Real progress has been made in eliciting the views of service users and carers (Person Centred Planning, Equal Lives Group, Big Picture Sessions, Learning Disability Consultation Group). A carer's charter is currently being produced on the Island which will provide a framework for developing support for carers. This charter will be based on extensive consultation and work previously undertaken in the production of a carer's strategy for the Isle of Man (2). There is still more to do in involving both service users and carers in the future planning, commissioning, delivering and monitoring of all services. The absence of a fully functioning partnership board restricts the participation of service users and carers in reshaping future support and services.

Learning Disability Partnership Boards

There are over 150 learning disability partnership boards in the U.K. The purpose of a partnership board is to provide strategic vision and leadership to formulate local objectives based on the priorities laid out in Valuing People and Valuing People Now. Effective partnership boards have properly constituted boards which include service users/carer leaders, commitment of senior service management (Director of Adult Social Care), representatives from all learning disability service providers and the Third Sector, health, education, employment and law enforcement. Partnership boards should form sub-groups based on the priorities contained in Valuing People Now and produce annual reports with local objectives. The Department of Health (3) has issued guidance on the creation and operation of effective partnership boards. This includes:-

- Having strong links with other local boards and commissioning bodies.
- Meaningful representation of people with learning disabilities and their family carers.
- Boards which follow the advice and guidance issued by the D.O.H. in compiling their annual reports.

References

1. Social Services' Act 2011, Part 3 Isle of Man
2. The Isle of Man Carers Strategy 2007-2010
3. 'Good Learning Disability Partnership Boards: Making it happen for everyone'. D.O.H. (2009).

Review of Previous Strategy 2007-2012

The overall objective of the first Isle of Man Learning Disability Strategy 2007-2012 was that all people with learning disabilities and their families will have greater choice and control over their lives and they will have the support of services to become empowered citizens. This initial strategy used a traffic light system to monitor and review its stated priorities and objectives. Priorities and objectives were grouped into the following categories: -

Housing and Accommodation

Achievements (Some in Partnership with Third Sector/Other Government Departments)

- The development of Carnane Centre for Autism, which provides accommodation and some day support for adults, operated by Autism Initiatives.
- Working in partnership with the former Department of Local Government and the Environment, five adults with learning disabilities have moved from residential services into their own homes, with individual tenancies supported by the Supported Living Service in both Douglas and Peel.
- A new four bed bungalow has been built and opened in Braddan.
- Cushag House has been commissioned in Port Erin, allowing the decommissioning of Windermere in the South of the Island.
- A number of older adults have successfully moved from residential services to independently operated older people's residential and nursing homes.
- There are now 18 adults with learning disabilities supported in their own homes by the supported living team. The proportion of people in supported living, compared to residential care, has increased from 5% in 2007 to almost 20% in 2012 (just 5% short of the five year target).
- Works programme to increase accessibility to, and within, residential homes has been implemented and monitored.
- The introduction of charging for adults in residential care has resulted in the money received being reinvested in the provision of a visiting psychology service and the development of services provided by Autism Initiatives/Short Break services.

Work In Progress/Partial Achievement/Not Achieved

- Off Island placements increased from 16 in 2007 to 18 as at July 2012. This includes the absorption of additional off Island transitional cases.
- Some contracting out of services has taken place, but the total number of known service users accessing the Third Sector, when compared to statutory services, remains small (approx 160 (30%) compared with 531 adults – see Prevalence Section - Table B).
- The provision of an additional home in the North of the Island to provide short-term breaks has been cancelled in favour of the expansion and creation of alternatives, including home-based breaks, holiday breaks, social and leisure breaks, adult placement and the expansion of residential respite facilities at Radcliffe Villas. Work has already taken place around the provision of home, holiday and social/leisure breaks. An identified Social Worker has been seconded to produce an operational model for the future provision of adult placement on the Island and a work schedule has been produced for the refurbishment of Radcliffe Villas.
- Options regarding the separation of housing and support ‘which devolves responsibility for the provision of accommodation to housing bodies’ has not expanded exponentially in terms of the number of service users and housing bodies.

Health and Wellbeing

Achievements

- A designated part-time Speech and Language Therapist was initially funded Manx Mencap to provide a service for adults with learning disabilities.
- Each service user has their own person centred ‘my plan’.
- Each service user has a specific health action plan.
- A series of training events/sessions have been provided for G.P’s and practice nurses to facilitate annual health checks for people with learning disabilities.
- A protocol has been developed for admission of adults with acute mental health problems to adult mental health services.
- A protocol is now in place for referral for assessment and diagnosis to a visiting consultant psychiatrist and psychologist.
- Sexuality policy in place.
- Consultation with people with learning disabilities and their families regarding sexual health has take place.

- Staff undergone training around issues contained in sexuality policy.
- Communications policy now in place.

Work in Progress/Partly Achieved/Not Achieved

- A standing multi-disciplinary group to collect/monitor/analyse health data, ensuring people with learning disabilities have equal access to quality health care, has not yet been established.

Fulfilling Lives

Achievements

- 'My Plan' approach, to monitor the implementation of person centred planning and evaluate progress, is operational for all adults with learning disabilities receiving residential and day services, operated by the Department of Social Care.

Work in Progress/Partly Achieved/Not Achieved

- Volunteer/Befriending service specific to learning disabilities did not materialise, although some progress has been made in establishing a working relationship with the 'live at home schemes' on Island.
- Extra one-to-one support, to meet the needs of individuals in transition, remains resource dependent.

Employment and Occupation

Achievements

- Responsibility for identifying work opportunities for people with disabilities and supporting those people in work, has transferred to the Department of Economic Development.
- A Social Firm business enterprise has been established which currently operates across a number of different sites. There are 44 people (8 attend more than one site) with a learning disability using the Social Firm.

- A number of new business initiatives have been identified by the Social Firm and funding from the Third Sector has been secured to increase the number of people in paid work in these proposed businesses.

Work in Progress/Partly Achieved/Not Achieved

- The overall percentage of adults with learning disabilities in paid employment in the Isle of Man is less than the average in England and Scotland.
- The Community Service Volunteer Scheme for job coaching and support has not been a success for various reasons.

Daytime Activities

Achievements

- Day Care and activities can now be organised for individuals in accordance with individual support plans, where possible.
- People now have greater choice of activities located away from the Day Centre.
- Day Service action plan (with targets) in place.
- Transport provision for service users has been re-modelled and is now being provided by Tours I.O.M., Taxi and Community Transport.
- Review of respite services was published in April 2008 (1). It echoed the priorities laid out in 2007-2012 L.D. Strategy (2) and the previous Respite Review in 2001 (3) which called for increased variety of short break options. Holiday breaks and increased social and leisure breaks are now available to service users.
- Expanded Day Care provision and choice through contract with Crossroads Care.

Work in Progress/Partly Achieved/Not Achieved

- Formulation of eligibility criteria, based on service user/carer need, required to ensure equitable access to short break services.
- Ongoing work into the formulation of Fair Access to Care Services and the proposed implementation of the Social Services Act (4) will entitle carers to an assessment of their own needs. The proposed plan to introduce charging for certain services (short-term

breaks) will generate income which will be re-invested in the development of respite and support services.

- Implementation of charging policy for respite services. Proceeds from charging to be reinvested in improved and increased short break services.
- Architectural plans have been drawn up and passed for the redevelopment of additional residential respite facilities at Radcliffe Villas.

Consultation, Partnership, Involvement and Advocacy

Achievement

- Advocacy service being restructured and new contracts to be in place with service provider.
- Series of 'big picture' sessions have taken place around the Island.
- Learning Disability briefing newsletters have been produced and circulated to stakeholders.
- A Departmental website
- Learning Disability Consultation Group operational.
- Ongoing dialogue with the Third Sector.

Workforce Planning, Training and Development

Achievements

- Residential Manager's Award programme completed for Senior Residential Social Workers in residential services.
- The management structure of both residential and day services has been reorganised since 2007.
- Induction programme in place for new staff.
- Basic communications training has been made available to all staff members.
- Mandatory training programme in place for all staff in day and residential services.

Work in Progress/ Partly Achieved/Not Achieved

- Day Services have 19 staff with NVQ Level 2 and 3 staff with Level 3 out of a total of 32 full-time/part-time staff (69%). Residential services have 100 staff with NVQ Level 2 and 15 with Level 3 out of a total of 170 full-time/part-time staff (68%).

- Day services have 3 managers with NVQ Level 4, 1 manager has NVQ Level 3 and 1 manager has NVQ Level 2 out of 4.5 F.T.E. Two managers are now working towards Middle Management ILM which is equivalent to NVQ Level 5. Residential services don't have any managers with NVQ Level 5, but 2 managers are working towards Middle Management ILM, which is equivalent to NVQ Level 5.
- The operational manager has completed I.L.M. Level 7.

Management and Supports

Achievements

- Review of Day Services' roles and structures completed in 2007.
- Learning Disabilities' structure reviewed since 2007.
- Registered Manager's Award Programme completed in 2007.
- Appraisal system set up and in place for all staff.
- A manpower service plan and succession plan is in place.

Work in Progress/Partly Achieved/Not Achieved

- NVQ Level 5 has not been completed by all senior managers. The Department has introduced Middle Management I.L.M. which is equivalent to NVQ for managers. There are currently 4 managers working towards Middle Management ILM.

Risk

Achievements

- A risk assessment is incorporated into each person-centred plan for each Department of Social Care service user. There is a risk forum (Clinical Management Meeting) where complex/high risk issues can be presented for multi-disciplinary peer review.
- A Departmental Risk Register is now in place. Each service area has its own risk plan.

Work in Progress/Partly Achieved/Not Achieved

- The creation of a Quality and Performance Improvements Manager post should be key to governance arrangements, risk and performance management for Adult Services.

Quality and Monitoring

Achievements

- Complaints and Whistle Blowing Policy in place and available on Government website. There have been 14 recorded complaints received since 2009. The subject of these complaints can be categorised as follows – 6 pertaining to quality of service, 4 regarding staff behaviour/concerns, 2 relating to access/level of service and 2 concerning mis-communication with services. 13 of the 14 complaints were dealt with at stage 2 and 1 at stage 3 of the Complaints Procedure.
- Learning Disability Services now produce annual key performance measures and a new performance framework for Learning Disability Services (including inspection reports) has been developed on Island. These performance indicators are forwarded to the C.E.O. on a quarterly basis and are used to highlight priorities and benchmark the Department's Service Delivery Plan (4).
- Registrations and Inspection Team in place and Minimum Residential Standards in place across all learning disabilities residential care homes, operated by the Department of Social Care.
- Person centred planning documentation in place for all individuals in residential care homes and Day Services run by the Department. Each individual has a minimum of 2 personal centre planning meetings per annum.
- 'Big Picture' sessions have ceased, but there is a standing Learning Disability Consultative Group where stakeholders can express their opinions regarding service provision and delivery.
- Both residential and Day Services input and monitor data pertaining to the individual service users (person centred planning process) and service activity (Quality Management Audit and Day and Residential Service Standards).

Work in Progress/Partly Achieved/Not Achieved

- The priorities and delivery plan was reviewed in November 2007 and June/July 2009.
- Organisations can learn to improve their performance if data received through the complaints procedure is collated and analysed annually.

References

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| 1. 'Evaluation Report on the Development of Respite Services for Adults with Learning Disabilities on the Isle of Man' (2008). |
| 2. The Isle of Man Learning Disability Strategy 2007-2012. 'Living life to the full'. |
| 3. 'Report on the review of respite services for adults with learning disabilities on the Isle of Man' (2001). |
| 4. 'Isle of Man Social Services Act' 2011 |

Prevalence – Understanding Local Needs

There is a lack of comprehensive data available regarding the exact prevalence of learning disabilities both in England and the Isle of Man. There is no information held centrally or available from population studies such as the census. For the purpose of this strategy it was necessary to obtain data from various sources and services on the Island and to corroborate the information collected by extrapolating data from the most recent research available in the U.K.

Review of Demographic Profile in England

As stated above, it is not possible to access a centralised data base regarding the number of people with learning disabilities in England. People with learning disabilities are living longer and are at greater risk of developing dementia compared to the general population. The vast majority (74%) of people with learning disabilities live at home with parents, relatives, partners or on their own in England. There are approximately 15% living in residential care homes, 10% are funded from supported living budgets and less than 2% in NHS accommodation (1 – P.6).

Information pertaining to children is collected from the Special Educational Needs (S.E.N.) units in schools. The definition of special educational needs is laid out in the 1996 Education Act, which states that children have special educational needs if they have a learning difficulty which calls for special educational provision. In 2006, there were 8.1 million pupils in all schools in England with approximately 1.5 million (18%) being categorised as having some sort of special educational need (2 – P.38). Emerson and Hatton state that in 2008 (1 – P.2) there were over 210,000 (2.6%) of pupils with ‘a primary S.E.N. associated with severe learning difficulty’. Of these 210,000 pupils, 7,350 (3.5%) have profound and multiple disabilities. It is estimated that the numbers of people with profound and multiple disabilities will increase by 1.8% per year, resulting in greater pressure on care and support services in England (3).

In a survey of people with learning disabilities in England, conducted in 2008 (1 – P.2) it was estimated that there were 985,000 people (2% of the general population) with a learning disability. Of these 985,000 people, 828,000 (84%) are aged 18 years or over. 177,000 people (21.4% of the adult learning disabilities population) were using services for people with learning disabilities, most, but not all, have severe/profound learning disabilities. It is

estimated that there are 174,000 adults (21%) with learning disabilities aged over 60 years. Emerson and Hatton adjusted their prevalence rates, taking into account increased mortality of people with learning disabilities, especially in the older age groups.

A previous study commissioned by Valuing People (4), estimated that 145,000 adults had a severe/profound learning disability and there were 1.2 million people with mild/moderate disabilities. Valuing people's prevalence estimates were calculated using a standard prevalence rate of 2.5% for mild/moderate learning disabilities across all age groups, thus giving inflated estimates, as they had not taken into account higher mortality rates for people with learning disabilities, according to Emerson and Hatton. They also point out that many adults with mild/moderate learning disabilities do not access specialist Learning Disability Services, which may reflect a lack of 'need' because of a wish to avoid stigmatisation and ineligibility for social care services.

Overall, the majority of people with learning disabilities live at home with parents or relatives. People with more severe or profound learning disabilities are more likely to be living in residential care. Most people receiving social care for learning disabilities are males under 65 years and females over 65 years. The 35-44 years age group has the highest proportion of males and females receiving social care in England. It is estimated that there will be a 5% increase in the number of people with learning disabilities between 2011 and 2021 (3 – P5), due to increased survival rates among young people and reduced mortality amongst older people with learning disabilities. The incidence and prevalence of Down's Syndrome is not decreasing, but life expectancy has increased significantly, with higher risks of developing dementia compared to the general population (5).

Prevalence of Autistic Spectrum Disorder/Conditions (A.S.D./A.S.C) in U.K

Autism, from the Greek meaning "self", was first included in the Diagnostic Symptoms Manual – 111 (DSM-111) in 1980. The original strict diagnostic criteria meant that a substantial number of children went undetected. Key elements around a triad of impairments (communication, social interaction and behaviours) were revised and included in a new classification known as "autistic disorder". In 1979 Wing and Gould (6) first proposed the life-long developmental disorder known as "A.S.D.", which includes the following sub-groups - Autistic, Aspergers, Rett's, Atypical Autism and Childhood Disintegrative Disorders (DSM-1V).

The prevalence rate and growth trends of A.S.D/A.S.C. in the U.K. have preoccupied the literature in recent years. A.S.D/A.S.C. prevalence rates vary from 90 per 10,000 population to 116 per 10,000 population, using ICD-10 criteria (7- P.20). The increase in prevalence rates over the last two decades may stem from a broadening of the A.S.D/A.S.C. concept and more inclusive diagnostic tools. The question of whether environmental factors such as diet, pollutants or allergies cause increased prevalence remains scientifically unanswered. An American study, published in September 2011 (8), stated there could be as many as 65% of children either undiagnosed or untreated. The National Autistic Society (N.A.S.) (10) estimated a prevalence rate of 100 per 10,000 (1:100) children have A.S.D. There are no prevalence studies available for adults with A.S.D. The gender ratio of children with Autism is 4:1 (male to female) across the full I.Q. range, rising to 9:1 among children (6- P.31) with Asperger syndrome.

People with A.S.D/A.S.C. may not experience a decline in general intelligence; estimates of the proportion of people with A.S.D/A.S.C., who have a learning disability (I.Q. Score less than 70) vary considerably. People with Asperger Syndrome usually have average, or above average, levels of intellectual ability and may never require input from services. In 2009, the National Audit Office (10) estimated that 48% of adults with 'low functioning Autism' receive support from Social Care, Health, Housing and Employment services. A summary of longitudinal studies (6 – P34) of people with A.S.D/A.S.C. found that the single best predictor of outcomes is I.Q. and the more severe a person's A.S.D/A.S.C. symptoms, the higher the degree of service involvement. Parents experience great concern and stress with regard to planning future care for their child, when they are no longer able to continue as the primary carer. Both parents and professionals agree on the future need for increased home and respite services, as well as greater provision of multi-disciplinary therapies.

Local Needs/Prevalence Estimates on the Isle of Man

The Isle of Man has a resident population of 84,497(11) as of the 27th March 2011. Undertaking a thorough prevalence/needs study attempts to establish how many people are likely to need Learning Disability Services and what type of services they will require. This should facilitate planning decisions to ensure that services, systems and structures meet the needs of people with learning disabilities and carers on the Island.

This strategy attempts to collect and collate information pertaining to the expected numbers of children and adults who have learning difficulties/disabilities on the Island by extrapolating for the population of the Isle of Man from data contained in contemporaneous research and surveys conducted in England. It then compares the expected numbers to the actual numbers of people counted, where possible (see Table A). This should provide a more accurate estimate of the numbers of people with learning difficulties/disabilities on the Island.

For the purpose of this strategy, we will then attempt to ascertain what services adults with learning disabilities are currently accessing and, thus, the approximate numbers of adults who may be currently living independently of services, but who may require future services in a crisis or emergency situation - illness or death of a parent/carer (see Table B).

Table A

Literature Review	England	% England	Extrapolated for IOM Population	% IOM	Actual Count IOM	% Actual IOM	Comments
People with a Learning Disability	985,000	2.0%	1,690	2.0%			
Children/Adults with a LD living at home	729,000	74.0%	1,251	74.0%			
Adults with a LD	828,000	84.0%	1,420	84.0%			
Adults with a LD Using Services	177,000	21.4%	304	21.4%	292	20.5%	
Adults with a LD over 60 years	174,000	21.0%	298	21.0%			
Pupils with SEN (18% of total pupil population in England - over 8.1m)	1,500,000	18.0%	2,101	18.0%	1,907	16.0%	1907 pupils identified as having SEN (2011/2012) = 16%
Pupils with Primary SEN Associated with Severe LD (2.6% of 8.1m pupils)	210,000	2.6%	303	2.6%	574	4.9%	Actual no. of pupils identified as having Higher Learning Needs (HLN) 574 (4.9%)
Pupils with Primary SEN Associated with Profound/Multiple LD	7,350	3.5%	11	3.5%	26	4.5%	There are 163 pupils in Special Needs Units (Sep 12 - Department of Education & Children). 26 are classified as having profound/multiple LD (PMLD) = 4.5% (26 of 574)

Total School Population England = 8.1M

Total School Population IOM = 11,671

IOM Population (84,497)

Interpretation of Data contained in Table A

Table A is divided into 8 columns which show the numbers of children/adults with learning disabilities, learning difficulties and A.S.D/A.S.C. in England, the second column shows the numbers extrapolated for the population of the Isle of Man whilst the third column is an actual count of people (where possible) on the Island.

Row 4, in Table A, estimates that there should be 304 adults with learning disabilities using services operated and funded by the Isle of Man whereas the actual number counted is 292. This would indicate that there are approximately 12 people currently living independently who could, at any future stage, require Learning Disability Services in the event of a breakdown in their natural support network.

Row 6 shows that the number and percentage of pupils in primary/secondary schools who have an identified SEN, is lower than expected in the Isle of Man. Classification and testing of pupils with learning difficulties/disabilities on the Isle of Man is different from the system used in England and it is beyond the remit of this strategy to explain this difference.

Row 7 illustrates that the number of pupils, with a primary SEN associated with severe learning disabilities, is significantly higher in the Isle of Man. Again, it is beyond the remit of this strategy to explain this difference.

Row 8 shows that the number of pupils with an identified SEN, associated with profound/multiple disabilities, is much greater than expected in Isle of Man schools. There are 26 identified pupils with profound/multiple disabilities, compared with an expected number of 11 pupils as extrapolated for the population of the Island. This will have major implications for future planning, allocation and provision of adult services. As already stated, people with profound/multiple disabilities depend heavily on adult learning difficulty/disability services.

Table B

Organisation (over 18 Years)	Total No. Of Service Users Accessing Each Service	Total No. of Service Users Accessing this Service Only
Residential Services	91	91
Day Services	113	9
IOM College	38	22
Crossroads Care	39	8
Social Work Team (total number of open cases)	92	63
Respite Services	46	0
Supported Living	18	15
Autism Initiatives (Outreach 26, S. Living 2, Day Support 3, UK Placement 4, Res 7)	49	42
Private Older People's Residential (7) /Nursing Homes (9)	16	16
Praxis	5	5
Temporary Adult Placement (TAP)	2	0
Off-Island Placement	18	18
Social Security Funded Adult Placement (SSAPS)	2	1
Community Support Worker/Psychologist	2	2
Total	531	292

Interpretation of Data contained in Table B

Table B illustrates what services known adults with learning difficulties/disabilities are using, both on and off Island. As previously stated, this table shows that there could be up to 12 individuals, when compared to the expected number extrapolated for the I.O.M. population (292 instead of 304), who may be currently receiving care and support independently from families/carers and who may require services commissioned by the Department of Social Care in the future.

This table also shows that the majority of Learning Disability Services available on the Island are provided directly by the Department of Social Care with only approximately 25% out of the 292 known service users receiving their service from the non-statutory or Third Sector. There are a total of 119 adults with learning difficulties/disabilities currently in residential accommodation on the Island (91 Residential Service, 7 Autism Initiatives, 5 Praxis and 16 Older Persons Res/Nursing Homes). There are also 18 adults in accommodation receiving support from the Supported Living Service operated by the Department of Social Care and 2

from Autism Initiatives. There are 18 adults in residential off-Island placements, making a total of 157 adult places funded by the Isle of Man (See Table B). This compares with a national average of 0.95 per 1,000 in residential care in England (12) or previous Government guidance in 2002 (13) of between 1.55 places and 2.35 places per 1,000 of the adult population with learning disabilities. Based on the 2011 census figures of the adult population (over 16 yrs) of 69,459, at the lower estimate, this equates to a figure of 108 places and, at the higher level, 163 places required for the Isle of Man.

It should also be noted at this stage that the provision of adult social care community services, such as the provision of adult placement schemes, shared ownership and supported living services, driven by the availability of direct payments, are at a more advanced phase in England than is currently the case on the Island.

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Future Demands/Needs

Valuing People Now (2009) and Valuing People Now: The Delivery Plan (2010-2011) identify key priorities for action, such as the creation of an effective partnership board in every local area, personalisation of support services, improvements in healthcare, increase the range of housing options, increase paid employment opportunities and improved joint planning and commissioning of services for people with learning disabilities. The above strategy emphasizes the importance of including everyone with learning disabilities, including people with complex/multiple needs, people with autistic spectrum disorders/conditions, people from ethnic groups and offenders in custody or in the community.

A number of challenges face those who plan and commission future services based on local prevalence data and the priorities set out in Valuing People Now. These include: -

- Creation of a local effective partnership board on the Island.
- A disproportionate increase in the numbers of adults with a learning disability who will develop dementia (see Prevalence section).
- An increase in the number of people requiring ground floor/adapted accommodation, due to age and disability.
- Caring for family members with learning disabilities who are reaching old age, is impacting on the caring ability and health of families. 75% of carers of an adult with learning disabilities have been caring for more than 20 years (1). Carers will soon be eligible for a carer’s assessment under the proposed Social Care Bill.
- Increased survival rates among young people with complex/multiple disabilities (see Table A – Prevalence Section).
- More young people are reaching adulthood with complex/multiple disabilities.
- People with learning disabilities are living longer.
- The forecasted spending pressures, linked to overall increase in demand, will necessitate a review of the benefits system and for people with learning disabilities on the Island.

We face a number of demographic, legislative, policy and economic changes which will impact on the current commissioning and service delivery arrangements; this strategy will strive to reflect these new circumstances.

References	
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A Case for Change

This section of the strategy examines the evidence around changing demands/needs, national and local policy drivers and planning/commissioning of needs-led services. It is estimated that a third of all adults with learning disabilities are living with a carer over 70 years old (1). As outlined in the local prevalence section, almost 80% of adults with learning disabilities are not accessing Adult Learning Disability Services but are being supported by families, friends and social networks on the Island. Consequently, service provision is centred on the provision of residential and day services, with almost 92% of the Department of Social Care in-house learning disability budget (excluding respite/short-term breaks, Social Firm and supported living services) allocated to residential and day services. The current balance of service provision and budget allocation, together with increasing demands, means more and more resources will be required to sustain this model which does not provide any support to almost 80% of adults with mild/moderate/high needs, who live at home with family carers.

The new agenda for services revolves around promoting independence, increasing choice regarding accommodation, support and social inclusion. In a survey of over 10,000 people with learning disabilities and carers, published in the Valuing People Now Strategy (p.6), the clear response was that people want to see a real difference in the range, quality and choice of services in their local areas. They want everyone to benefit including people with more complex needs, people on the autistic spectrum, people from ethnic minorities and those who have offended. They also want more recognition of the important role and expertise of family carers, in the support of people with learning disabilities. They wish to be involved in the designing, planning and development of local services.

The current lack of an evidence-based service framework (apart from inspection reports and some process measures – K.P.I's.), the projected increase in expectations/demand for services and the proposed introduction of new legislation, will challenge the current model of service provision for adults with learning disabilities in the Isle of Man.

Increased Demands/Needs

- An increase in the total number of people with learning disabilities – 5% over the decade 2001-2011 (2).

- An increase in the number of adults with learning disabilities aged over 60 years.
- More people with mild/moderate learning disabilities will become known to services.
- This will result in increased numbers of people using services. Valuing People Now (3) estimates that the number of people using services will increase by 50% by 2018.
- The numbers of people with complex/multiple disabilities are increasing, due to better survival rates.
- An increase in the number of people with learning disabilities and dementia.
- The number of diagnosed people with autistic spectrum disorders/conditions is increasing. This will translate into increased demand for educational services, adult services and a range of accommodation options. Parents with a son or daughter with A.S.D/A.S.C. constantly worry about their child's future and often ask the question 'What will happen to them when I die'. (4).
- There is also a large number of adults with A.S.D./A.S.C. who have not yet had access to a formal diagnosis, so there is the issue of both the growth of newly diagnosed cases and the identification of existing adults with the condition.

Changes in Legislation/Policy

- The proposed introduction of the Social Care Act sets out the Department's duty to provide carers with an assessment of their own needs. Family carers of people with a learning disability have often made a life-long commitment to caring and need support, especially as they become older. The introduction of a carer's assessment may reveal previously unidentified need, such as access to respite/short-term breaks, support to access a life beyond caring and financial support. The imminent introduction of the Regulation of Care Bill will also provide a robust and proportionate regulatory system for statutory and Third Sector care services and will provide extra protection for vulnerable people.
- People with learning disabilities and their family carers wish to see a greater range and choice of services and wish to be involved in the design and planning of future services, as evidenced by the aforementioned survey. These views have now been enshrined in national policy and in the growth of local partnership boards in the U.K.
- The successful introduction of standards and inspection for adults with learning disabilities, living in residential care, was an initial step to safeguarding vulnerable adults residing in the Isle of Man. The proposed introduction of the Regulation of Care Act will provide further protection for statutory and non-statutory service users and extend regulation to cover Adult Day Centres and Home care which are currently unregulated.

References

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Service Areas and Priorities

The challenge facing Learning Disability Services on the Isle of Man is to meet increasing demand, within allocated resources, whilst moving towards greater personalisation and improved performance. A recent report commissioned by the Department of Social Care recommends that future expenditure should be directed away from institutional care and towards ‘a model of care that seeks to maintain service users independence through community care’ (1). This report also states that we must change our focus to ensure more effective planning and commissioning of services that ‘will allow service users needs to be met by an appropriate mix of services and will be more financially viable in the longer term’.

Current Provision

As previously outlined in the Prevalence section, only 292 people out of an estimated total population of 1,420 adults, access all Learning Disability Services funded by the Department of Social Care. Over two-thirds of the above 292 adults access services provided directly by the Department of Social Care, whilst less than one-quarter access services provided by the Third Sector (see fig. 1a). The vast majority of expenditure (almost 99%) is on residential and Day Care services (see Fig 1b).

Fig 1a **Adult Learning Disabilities - No. Of Service Users**

■ DSC - Department of Social Care ■ DEC - Department of Education & Children ■ TS - Third Sector

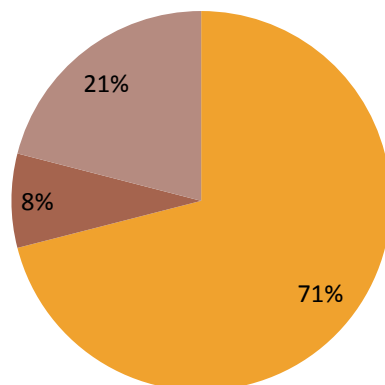
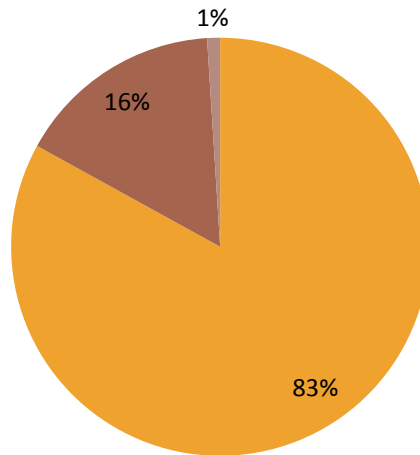


Fig 1b

Adult Learning Disabilities - Expenditure

■ RC - Residential Care ■ DC - Day Care ■ SL - Supported Living



There are 91 residential places provided by the Department of Social Care, 5 provided by Praxis and 7 provided by Autism Initiatives. There are a total of 18 people receiving a service from Supported Living operated by the Department of Social Care and 2 from Autism Initiatives. A total of 16 older people with learning disabilities are resident in private nursing/residential homes on Island. There are also 18 off-Island residential placements, making a total of 157 housing and support places, which is above the minimum level of 1.55 per 1,000 of the adult population (I.O.M. = 108).

There are 113 adults receiving Day Care from Eastcliffe Day Centre, Mooragh View, Greenfield Garden Centre and E.R.I.C. In addition, there are 39 people receiving day support from Crossroads Care and 3 from Autism Initiatives. A total of 46 adults use respite or short-term breaks service provided by the Department of Social Care and 26 receive outreach services from Autism Initiatives (see Fig. 2). There are currently 2 people who receive a temporary adult placement service on the Island.

Fig 2

Service Type	DSC	TS
Residential Care	91	12
Day Care	113	42
Supported Living	18	2
Short-Term Break Service (Respite)	46	26
Total	267	82

Priorities

In keeping with Valuing People Now (2), the four priorities for services will centre on: -

- Employment
- Housing
- Health
- Including everyone/personalisation

Whilst adhering to the principle of valuing all people, including people with complex needs, this strategy proposes a shift away from residential care services and Monday to Friday, 9.00 a.m.- 5.00 p.m., day services towards more personalised community care packages. The development of supported living, supported housing with flexible levels of support, short-term breaks, adult placement and employment/work opportunities, must be prioritised. The 2007 U.K. 'Putting People First' report (2) states that social care services should ensure that all people who need extra support in their lives, should be supported to live in their own homes for longer and be able to use mainstream community services. This shift in focus towards more individualised, flexible, needs led community support, is summarised in Fig. 3

Fig. 3

<i>We Need Less</i>	<i>We Need More</i>
<ul style="list-style-type: none"> • Residential Care Services • Traditional Day Services 	<ul style="list-style-type: none"> • Supported Living, Supported Housing and Adult Placement • Supported accommodation for people with complex needs • Work and employment opportunities • Established individualised budgets in a phased way

This strategy proposes to sub-divide the above four priorities into sub-sections for more detailed analysis.

Employment

Work

- 8% of the estimated total population of adults with a learning disability, of working age, are in open/paid employment in England (3). People with mild/moderate learning disabilities are more likely to obtain paid employment compared with severe disabilities. In Scotland, 16% of adults with learning disabilities are in employment and 29% of these are in open/paid employment. This equates to approximately 5% of all adults with a learning disability in Scotland (4). In the Isle of Man there are 61 adults known to Learning Disability Services currently in employment, of which 33 are in paid work (assisted by the Disability Employment Service/Supported Employment) and 28 in unpaid employment. This corresponds to almost 21% of adults using Learning Disability Services in employment and over 11% in open/paid employment on the Isle of Man. This equates to approximately 4.3% of all adults with learning disabilities on the Isle of Man.
- The objective is to increase the number of people in paid employment, which will enable a planned reduction of Day Care places by the end of this strategy. This will require the development of a range of employment options in partnership with employers, disability employment service, Social Firms, I.O.M. College and the Third Sector, without a loss of capacity whilst transition takes place.

Social Firms

- A Social Firm has already been established and currently operates within Day Services' organisational structure. It comprises of two separate units (Greenfield Garden Centre, E.R.I.C. and Supported Employment). The objectives of both Greenfield and E.R.I.C. include developing working skills and preparing people for paid employment. The 36 people who access the units do not receive a wage, but an 'incentive payment' of £3 per day, paid from Day Services' budget. It generates income, which is reinvested in equipment and materials. Supported employment was set up with financial assistance from Manx Mencap and currently supports 7 people.
- There is a 5 year plan which outlines the future vision of becoming a separate stand-alone charity/business, which will pay workers the minimum hourly wage, provide work opportunities for school-leavers with a learning disability, provide specific work related training and have significant worker representation on the board of directors. It will be in

a position to accept grants/donations directly and avail of V.A.T refunds charged to customers. The plan is to expand the range of activities and services provided by the Social Firm and, ultimately, to be self-financing. Future support will be provided by paid and volunteer staff who will undergo specific training, provided by a Social Firm in Birmingham.

Day Services

- As previously noted, the vast majority of Day Services, spread across a number of sites, are provided directly by the Department of Social Care on the Isle of Man. Activities undertaken at Day Services include delivery of personal care, work (Social Firm), group activities, craftwork, I.T. skills training, independent living skills and drama. Almost 11% of all adults with learning disabilities (Department of Social Care- 113, Crossroads Care - 38, Autism Initiatives- 3) attend day services compared with 29% in Scotland (4). 27% of adults have some form of alternative day opportunities in Scotland.
- Day services are currently free at the point of delivery on the Isle of Man. The revenue cost of providing day services, provided directly by the Department of Social Care is £10,398 per person, per annum. Valuing Employment Now (5) states that resources should be redirected away from day services and education into supported employment and work training programmes. Independent analysis of costs and outcomes has shown that the cost of a supported employment programme is half that of a place in day services (8).
- The provision and role of traditional Day Centres, for adults with learning disabilities, has changed in the U.K. (2, 5, 6). The number of adults attending Day Centres has dropped, whilst the number accessing alternative day opportunities and employment have increased in the last five years (7). This increase in alternative day opportunities has been facilitated by the demand for personalised services, funded by people's personal budgets. Day Services have been remodelled to provide work opportunities (recycling, catering, woodwork, and gardening) and activity focused activities. The UK Government's stated intention is to increase the number of people, with learning disabilities, in paid employment and have implemented a programme to develop a pathway into paid employment for young people leaving school or college.

There is commitment from Department of Social Care management and staff to change day services and a working group is considering a number of objectives to be implemented over the life of this strategy including: -

- Increased support work/job opportunities, including the introduction of a pathway to work for young people leaving school/college. A range of employment opportunities need to be developed without resulting in a loss of capacity in the system, whilst transition takes place. Co-operation with the disability employment service, college, Third Sector providers and employers could be planned and facilitated through a sub-group of the proposed Partnership Board.
- A target number or percentage of adults with learning disabilities in paid employment should be set by the representatives from the relevant agencies on the employment sub-group of the proposed Learning Disabilities Partnership Board
- Increased and more flexible learning and life opportunities should be developed and evaluated both by the Department of Social Care and Third Sector.
- Day Services operated by the Department of Social Care to focus on specialised services for people with profound/multiple needs. Autism Initiatives or another provider should offer increased personalised life and work opportunities for people with severe Autism.
- Better services to meet health and personal care needs of people with profound and multiple learning disabilities.
- A planned reduction of day service places, with a corresponding increase in supported employment, through the Social Firm framework, should happen over the next five years.
- The Third Sector should develop a mix of employment, further education and community support services, thus complying with the recommendations contained in the recent Scope of Government in the Isle of Man report (8). Alternative agencies should support adults to access mainstream services and assist them to progress educationally and live a full life.
- Involve adults and carers in future planning, access and delivery of services. At present, some people with disabilities, who wish to access alternative opportunities, do not receive a service.

Housing

Residential Services

- There are currently 91 people living in 21 community homes/units operated by the Department of Social Care and a further 12 places provided by the Third Sector (Praxis

and Autism Initiatives). There are approximately 16 people in private nursing and residential homes on the Island. There are also 18 people in residential off-Island placements. There are no specific beds available within Health Services for adults with learning disabilities in the Isle of Man. The Isle of Man currently provides/purchases 137 residential places which is at the mid-upper end of the range of 1.55 and 2.35 places per 1,000 of the adult population. The ratio of residential places (87%) to supported living (13%) is too high and targets should be set over the lifespan of this strategy to increase the proportion of people living in their own homes with a support package.

- As noted above, 87% of on-Island residential places are funded, managed and operated by the Department of Social Care. Residential care, operated directly by the Department of Social Care, accounts for 83% of the total on-Island revenue budget (2011-12) or approximately £65,800 per person, per year (See fig.1). This compares with the Praxis budget of approximately £106,000, per person, per year. It should be noted that the degree and range of learning disabilities associated with the people in residential care, varies considerably across the homes operated by the Department of Social Care, whereas Praxis provides a residential service for 5 people with profound/multiple learning disabilities. The cost of off-Island placements is approximately £93,200 per person, per year.
- Residential care should continue to be available for those people with a learning disability who actively choose it, but greater emphasis needs to be placed on developing alternate models of providing services which offer people the housing and support that they want. The majority of people with learning disabilities, in residential care, do not achieve the Valuing People ambition of choice of where and who they live with. Service planners need to develop a range of accommodation and support options, such as shared ownership, supported housing and more supported living.
- People with learning disabilities and their families need to plan how they can reconcile their wishes with the different types of housing and support that can be made available. Although alternative models of accommodation and support need to be developed and increased, residential care will continue to be a resource for specific groups of people with profound/multiple disabilities who may be affected by the Turnbull judgement and those at risk of losing their home.

Future objectives for residential services should include: -

- To re-assess the needs of adults currently in Department of Social Care residential care and explore, with the assistance of the advocacy service, alternative options for the future provision of accommodation and support.
- Determine the future size, scope and structure of residential services managed and operated by the Department of Social Care
- To promote greater independence and choice for adults with learning disabilities by rebalancing the proportion of residential care and alternative accommodation and support options, in accordance with the principles contained in Valuing People Now and current best practice.
- To re-appropriate surplus monies from the proposed re-configuration of residential services into the development of supported housing, shared ownership schemes and supported living.

Supported Living

- Supported living was developed in England during the 1990's as an alternative to the predominant model of residential care for adults with learning disabilities. It separates the service functions of providing accommodation and support. The separation of accommodation and support means that the support package, or even support provider, can be changed without jeopardising the person's accommodation rights. This enables people to live as independently as possible, by offering choice and control with regards to where they live, who they live with and how they live their lives. In England, supported living services must be registered under the Health and Social Care Act 2010 and are governed by a set of principles which are incorporated in the Reach Standards, which are designed to place more control and choice in the hands of the service user.
- There are different models of supportive living, ranging from a person receiving a few hours of support in their rented home, to 24 hour support/care in a person's privately owned property. The effects of the Turnbull judgement, which limited housing benefit to market levels on adults with learning disabilities in the U.K., has thrown the whole prospect of providing supported living for people with profound/multiple disabilities into confusion. The main differences between supported living and residential care can be summarised as follows (9):-

Fig. 4
U.K. - Summary of main advantages for supported living over residential care.

Supported Living	Residential Care
Own home or tenancy. Security of tenure.	Licence agreement with no security of tenure.
As a tenant or homeowner the person has a right to choose who provides their support and can change support arrangements without moving home or move home without changing support arrangements.	Support is provided as part of a package with housing and either element cannot be changed without impacting on the other.
Tenants and homeowners have rights to full welfare benefits including housing benefit, income support and disability living allowance.	People in residential care have rights to limited amounts of welfare benefits.
Can access Direct Payments, Personal Budget, Supporting People Grant and Independent Living Fund for support.	Cannot access most additional funding for support.

In the Isle of Man there is a small supported living service which provides floating support to 18 adults residing in their own homes. Each person has their own individual support package, which is designed and reviewed in conjunction with the person concerned. It is envisaged that the supported living service will be regulated under the new Regulation of Care Bill, when enacted. The revenue budget for the supported living service is £226,000 in 2012/13, which equates to approximately £12,500 per person, per annum. The recent tribal review of services (1) stated that supported living and supported housing options are under-used in the Isle of Man, compared to the U.K., due to ‘an historical tendency to select residential options for adult social care users’. Therefore, the objective is to expand the supported living service and assist more people to live in their own homes, even if their support needs are enduring and there is little prospect of support ceasing to be required. Future service objectives should include: -

- Support the transition and develop a pathway for people with learning disabilities and A.S.D/A.S.C. who wish to move from their family home to their own home.
- A range of housing options (ownership/supported housing) should be developed, in conjunction with local housing providers and the Third Sector (i.e. Manx Mencap).
- People with learning disabilities/A.S.D/A.S.C. assessed as having moderate need or above, should be provided with the individual support packages they require.

Implementation of the Social Services Act and the proposed introduction of Fair Access to Care Services should ensure this occurs in the future.

- Support identified people to transfer from residential care to supported living/supported housing with their own individually assessed packages of support. Savings from closure of community homes to be re-invested in supported living/supported housing programme.
- Services for people with low-level needs are provided through ‘floating support’. This will require staff with appropriate training and skills in this area of service provision. This service could be provided by a Third Sector organisation.
- Supported living services are not currently subject to external audit or inspection on the Island. In the interests of promoting quality and safeguarding, this should be addressed by the proposed Safeguarding Adults Board (see safeguarding).
- Support services (adult placement/short-term breaks) should be developed and expanded for people living in the family home who are being looked after by carers. This service could be provided by Third Sector organisations, in accordance with the recommendations contained in the review of the Scope of Government in the Isle of Man (8).

Supported Housing

Supported housing refers to housing that has been designated for use by people with learning disabilities. It separates housing and support functions and allows people to change either element without affecting the other, as people have their own tenancy agreement. Supported housing has, in recent years, become the preferred type of accommodation for people moving on from the family home. Various models of supported housing have been developed across England, in keeping with the principles of promoting choice and social inclusion for people with a learning disability. These different models (outlined below) provide people with more choice and control over where, and with whom, they live (9).

To replicate the introduction of supported housing models in the Isle of Man will require a redesign of current services and a shift of investment away from residential care to supported living and supported housing models of service delivery (see figure 1). Feedback from the recent Isle of Man Housing Review (10) shows strong public support for an increase in extra care and supported housing for vulnerable people, including adults with learning disabilities.

- Shared supported housing is the oldest and most used model operating in England. It gives people with learning disabilities restricted choice of where and with whom they live. In the past, this model was created to provide more choice and control for people compared to residential care. There was and is demand for this model of housing and support. This shared model has been criticised for offering limited choice of whom the person wishes to live with. Young people leaving their family home rarely wish to share with older people. Therefore, shared housing needs to be carefully designed and planned to ensure people have their privacy and own personal space such as en-suite rooms and more than one communal area. In the Isle of Man, the community homes managed and operated by the Department of Social Care are broadly equivalent to shared supported housing in England, although there is no clear separation of housing and support.
- Extra care is provided to people with a learning disability in their own property/flat within a small, wider accommodation complex, sometimes referred to as sheltered housing. This has the benefit of allowing people to live in close proximity, but who do not wish to live together. People may choose to rent, part buy or purchase the accommodation outright. Support is provided in accordance with a mutually agreed support package. This model should be restricted to small numbers to avoid the inherent risk of segregation and stigma. This model lends itself to the development of extra care housing schemes for older adults with a learning disability and dementia.
- Shared lives (please see Adult Placement).
- Community living networks, such as the Keyring model, have been in operation for many years in England. It supports people within a designated boundary area and recruits a volunteer to offer limited amounts of support and to assist in helping people living within the boundary area to access local services and to support each other. Each area employs a volunteer co-ordinator to support and supervise volunteers. A similar model for older people (Living at Home Scheme) already operates successfully across the Isle of Man.

Shared Ownership/Home Ownership

- Access to mainstream housing is fundamental in enabling people with learning disabilities to live more equal, ordinary and socially inclusive lives. It gives people with learning disabilities real control and choice over where they live, who they live with (if anyone) and how they are supported.

- The first shared ownership schemes were introduced in England during the 1980's to help people who could not afford to buy their home outright. The person buys a share of a property, usually between 25% and 75% and pays rent on the remainder (11). The person can buy more shares and, if they wish, own their own home outright. This scheme suits people who are in part-time employment and/or receive appropriate benefits.
- In England, shared ownership schemes are operated by registered housing associations or registered social landlords. These are regulated and audited by H.C.A. and T.S.A., both Government agencies. Shared ownership schemes are becoming increasingly successful in helping individuals, couples and friends to buy their own homes and choose where they live.
- In the Isle of Man, the role of registered housing association could be undertaken by the Third Sector which could be regulated by the Department of Social Care
- Other home ownership options, which could be adapted and applied in the Isle of Man without major legislative delays, include outright ownership, family funded shared ownership and purchasing on the open market using the Government's first time buyer's scheme.

Residential Respite/Short-term Break Services

There is one residential respite service for adults with learning disabilities managed and operated by the Department of Social Care on the Isle of Man. Hollydene is a seven bedroom respite facility which currently offers some social/leisure breaks, holiday breaks, emergency breaks and overnight stays to 46 different people with moderate to profound/multiple disabilities. Autism Initiatives and Crossroads Care provide day support and outreach services to approximately 65 adults with a learning disability on the Island. Respite/short-term break services are currently free at the point of delivery to all service users.

A report on the development of respite services on the Island in 2008 (12) made ten recommendations, which centred around expanding the range and amount of respite services and the introduction of a charging policy for overnight stays and meals, which would be reinvested in developing and improving future services. An evaluation of progress made, is the provision of respite services, due for completion early next year. Recommendations from the above report include the development of: -

- Involvement of families/carers (Carer's Assessment).
- Development of eligibility criteria.
- Family based breaks (Adult Placement).
- Home based breaks.
- Community, social and leisure breaks.
- Holiday breaks.
- Introduction of charging for overnight stays and meals. Proceeds to be reinvested in the development/improvement of services.

Health

The healthcare needs of people with learning disabilities are well documented. Good healthcare and preventing ill-health is very important for people with learning disabilities. The Disability Rights Commission (13) found that people with learning disabilities have higher rates of obesity/respiratory disease, diabetes, sight impairments, dental problems, early-onset dementia, epilepsy and other associated disabilities or health problems than the general population. Therefore, supporting people to access primary and secondary healthcare is essential in maintaining good health.

Much work has been done on the Isle of Man to address the health needs of people with a learning disability, such as the introduction of annual health checks for those in residential care, the introduction of G.P. registers of people with a learning disability and protocols for access to mental health and psychology services. However, more needs to be done to extend people's longevity and quality of life, such as the early specific screening of people with Down's Syndrome for dementia and helping all those people with incurable/progressive illness or who need palliative care. Maintaining the focus on improving the healthcare needs for people with learning disabilities is one of the key priorities of Valuing People Now and the objectives for both health and social care services in the Isle of Man should include: -

- Monitor and evaluate the roll-out of G.P. practice registers of people with learning disabilities throughout the Island.
- Evaluate the percentage of all people with a learning disability on G.P. practice registers who receive an annual health check.

- Monitor/evaluate health care performance indicators of all people with learning disabilities/Autism spectrum disorders(conditions) who are involved with services provided both by the Department of Social Care and the Third Sector.
- Create a sub-group of the proposed Learning Disability Partnership Board (Learning Disabilities Partnership Board) to collect and analyse health and social care data such as access/uptake of primary care services, including dental and optometry services, for people with learning disabilities.
- This sub-group should also develop pathways in accordance with the Right Care Project (14).
- To focus on improving health promotion for people with learning disabilities on the Island. Sub-group of the Learning Disabilities Partnership Board to formulate programme for improving health promotion advice provided by front-line health and social care staff.
- Provide equality training through the Learning Disabilities Partnership Board for front-line health and social care staff.
- To monitor protocol between learning disability and mental health services, particularly in relation to access/waiting times.
- Develop a specific pathway in conjunction with Older People’s Mental Health Services for early screening of people with Down’s Syndrome who are at greater risk of developing dementia.
- Develop a care pathway for the delivery of palliative and end-of-life care for adults with learning disabilities (see End of Life Care).
- Monitor and evaluate the crisis intervention resolution agreement with Mental Health Services.

Including Everyone / Personalisation

This strategy attempts to adhere to the principles contained in the U.K. Strategy, Valuing People Now (V.P.N.). The overall objective in V.P.N. is that all people with learning disabilities and A.S.D/A.S.C. will be supported to become empowered citizens. This includes all groups of people with a learning disability, some of whom are least often heard and sometimes excluded. These groups include people with complex needs, challenging behaviours, people on the autistic spectrum, people in the criminal justice system and from ethnic groups.

The involvement of adults with learning disabilities and their family carers in planning and shaping of their services will lead to real progress in improving their daily lives. The

increasing use of person centred planning has helped people design their own support packages and promote choice. The promotion of choice and control to help people maintain their own personal support networks, rather than services replacing individual networks, is one of the main aims of this strategy. This shift in power and control away from services must be accompanied by more inclusive and revised systems which allow more people with learning disabilities and A.S.D/A.S.C., who are eligible for support, to be included in the commissioning of services. This should result in better forward planning and commissioning of services which are linked to the level of need of the people who require them.

Eligibility

Assessment of needs of eligible carers will become a legal duty under the new Social Services Act 2011 (15). Under Section 11 of the above Act, eligible carers (as set out in Section 6 of the Act) will be entitled to request an assessment of their ability to provide, or continue to provide, care if it appears to the Department that:

- ‘(a) a person provides or intends to provide another person with a substantial amount of care on a regular basis and
- (b) that other person is a person for whom the Department may provide or secure the provision of social care services in the community’.

Carers carrying out work under a contract of employment or by a volunteer for a voluntary organisation are excluded.

Under the new Act, the Department, following an assessment, will provide a written statement detailing if the person has/has not needs which require the provision of carer support services. Depending on the outcome of the assessment, a carer could be entitled to carer support, which may be provided or secured by the Department.

In England, approximately one-third of all carers receiving community based services in 2008/09 were carers of people with learning disabilities (16).

Safeguarding

The key priority of personalisation needs to be balanced with a requirement to ensure that people can live their lives safely. Risk management should be carried out in the context of

facilitating choice and independence, not control and confinement. Safeguarding vulnerable adults and risk management is a priority for the Department.

A vulnerable adult is a person 'who is unable to protect himself or herself against significant harm or exploitation' (17). The introduction of standards and inspection of adult learning disability residential services and the roll out of the vulnerable adults and risk management policies, have helped to identify and manage the risks for those people receiving residential care. Supported living services are not currently subject to external audit or inspection. There were 14 recorded complaints made pertaining to all Learning Disability Services between 2009 and 2012. No breakdown of the nature/outcome of these complaints was readily available. Safeguarding against the risk of abuse/neglect necessitates that services respond appropriately to allegations and that all data, information and recommendations are collated and mapped to ensure consistent outcomes.

Both the Cornwall (18) and Winterbourne View Inquiry Reports (19) into abuse of adults with learning disabilities identified that commissioning and provision of services, irrespective of national policies and guidance, were contributory factors to unacceptably poor practice and ensuing abuse in the U.K. This failure to adhere to contemporary principles, priorities and regulations, coupled with inadequate response to complaints, led to unnecessary suffering for service users. The absence of choice of where people lived and with who they lived with was of particular concern in the Cornwall investigation into their supported living service (P.6-7) which was comparable to the provision of residential community homes on the Island. The personalisation of services and involvement of people with learning disabilities and their family carers, in the development and provision of their own accommodation/support services, is one of the priorities of this strategy.

Safeguarding vulnerable adults is not the responsibility of one department or agency and in most areas in England there is a local Safeguarding Adults Board made up of representatives from Social Care, Health, Police, and the Third Sector. These Safeguarding Adults Boards monitor implementation of changes in policy and practice, analyse complaints and investigations and the roll-out of safeguarding awareness training to people with learning disabilities and appropriate staff. One of the tasks of the proposed Safeguarding Board will be to ensure that the recent and worrying phenomenon of 'hate crime' is understood and reported on the Island. It will also need to develop reporting/response mechanisms in keeping with best practice and guidelines. This Safeguarding Board should convene a sub-group of the proposed Learning Disabilities Partnership Board to act as a

working group, focusing exclusively on safeguarding issues. Future objectives for promoting safeguarding should include;-

- Establishment of a Safeguarding Board – the Department is in the process of formulating proposals around the establishment of an Safeguarding Adults Board.
- Safeguarding Board to produce and submit annual reports to Learning Disabilities Partnership Board
- Develop secure mechanisms for reporting/responding to reports of crimes committed involving adults with learning disabilities.
- Residential services to provide documented choice of where/with whom people live (where possible) and greater control over the type of support they receive.
- Introduce proposed external regulation of supported living services.
- Upgrade the procedure for collection/collation of information pertaining to the type and characteristics of complaints received by all learning disabilities services. This information needs to be passed on to the Safeguarding Board within an appropriate timeframe. The Department has recently convened a forum to incorporate issues in response to the Winterbourne Review.
- Develop safeguarding easy-read information packs for adults with learning disabilities on the Island.

Advocacy

Valuing People Now stresses the importance of people with learning disabilities being able to express what they want from their lives with support from advocacy services. Advocacy enables people with learning disabilities to understand their rights under the Human Rights Act and ensure that their views/opinions are expressed and listened to. V.P.N. describes the different types of advocacy, including: -

- Self advocacy – people coming together to speak up for themselves.
- Citizen advocacy – volunteers developing long-term relationships with people and speaking up for them.
- Professional or representational advocacy – people being paid to advocate with, and for, individuals on a short or long-term basis.
- Peer advocacy – people who have the same or similar experience of discrimination as the person they are acting as an advocate for.

In the Isle of Man, professional advocacy services are provided through United Response, which is a U.K. learning disability charity. United Response has an Advocacy Manager based permanently on the Island who enables people to: -

- Make choices
- Have independence
- Exercise their rights
- Be included in society

United Response helps operate two equal lives groups, which are self advocacy groups. It provides individual advocacy support for people who need help with specific issues and those in crisis situations. Supports people in transition and to attend regional advocacy conferences and training. It also participates in working groups and meetings which monitor and contribute to service development on the Island.

United Response produces quarterly partnership meeting reports, which are forwarded to the Department of Social Care senior managers. These reports include issues and concerns of adults with learning disabilities residing in the Isle of Man.

Complex/ Multiple Needs

Valuing People Now places special emphasis on meeting the needs of people with more complex and multiple needs. It also focuses on the needs of families/carers and how services are planned, commissioned and delivered to best support them in the future. It is vital that services understand the needs of people with complex and multiple needs, and their families, and make adaptations to service design and delivery in partnership with other services.

Although we cannot change the nature of people's disabilities, services should constantly strive to promote people's rights and work towards greater participation and inclusion in society. Like everyone else, people with more complex and multiple disabilities will continue to learn and develop throughout their lives and should be offered the support and opportunities to learn new skills.

A national review of services for people with learning disabilities and complex needs in England (20) found that services had made some progress in providing more personalised services, but there has not been 'substantial, systematic, properly resourced services to meet the needs of local populations'. The review stated that people had more person-centred planning, more choice in housing and day activities. The vast majority of adults with complex/multiple needs did not have access to supported paid/unpaid employment, had problems accessing health care and mental health services and the review highlighted deficits in safeguarding arrangements.

As stated previously in this Prevalence section, the Isle of Man has a greater percentage of pupils with severe and profound/multiple learning disabilities than expected in the educational system. Learning Disability Services should be planned to support people with additional needs associated with communication, physical/health, sensory, behavioural and mental health conditions. Adults with complex/multiple learning disabilities receive high levels of care and support from families, which should be complimented by good person-centred flexible skilled support from services to help maximise their potential as valued citizens. Services should work in partnership with families, friends, volunteers and professionals to help develop effective 'circles of support' to help the person achieve their personal objectives and promote social inclusion. Greater access to personalised daytime activities and supported paid/unpaid employment should be a priority for services. Promoting better engagement with local health and mental health services and safeguarding should be addressed through the proposed sub-groups of the Learning Disabilities Partnership Board

Challenging Behaviour

The term, challenging behaviour, refers to those behaviours that represent challenges to services, rather than problems which are solely intrinsic to the individual with learning disabilities. These behaviours may not always be life threatening but they can significantly interfere with the quality of life for those who live in the same accommodation and those who care for individuals who exhibit such behaviours. Challenging behaviour can include aggression (physical and verbal), self harm, destructiveness and disruptiveness. It is often seen in people with learning disabilities or with A.S.D/A.S.C. who have extensive communication difficulties.

The 2007 Mansell Report (21) identified a number of important areas in the U.K. where improvements can be made in commissioning better quality and more cost effective services for people with challenging behaviours. These include: -

- Services having a commitment to the principle of ‘an ordinary life’ and working in partnership with people, who exhibit challenging behaviours, and their families.
- Close working relationships between health and social care and the appropriate multi-disciplinary professionals.
- Use of person-centred approaches in service design and delivery. Separation of accommodation and support are good indicators of successful services.
- A skilled support staff team and genuine senior management involvement is necessary for the delivery of high quality services.
- Evidence based practices and the development of an outcomes framework help demonstrate progress and cost effectiveness.
- Upfront investment to ensure skills and resources are available in the early stages is necessary to ensure long-term effective and efficient local services for people with challenging behaviours.

The Adult Learning Disability Service on the Isle of Man does not have a designated service which specialises in applying behavioural analysis to helping people with learning disabilities who exhibit challenging behaviours. A number of residential community homes have residents who have and still do display challenging behaviours. The service also receives referrals through the Adult Services Access Team for assessment of people living at home who exhibit anti-social or mal-adaptive behaviours. The Adult Learning Disability Service employs a full-time qualified Community Support Nurse, who has undergone specialist training in the assessment/management of people with challenging behaviours. The service also has access to a visiting Clinical Psychologist and Consultant Psychiatrist. Although, no documented service wide evaluations exist regarding the effectiveness and efficiency of behavioural interventions, there are individually documented examples of success in helping to decrease the severity and frequency of such behaviours.

Autism Spectrum Disorder/Conditions (A.S.D/A.S.C.)

The broadening of the autistic spectrum disorder/conditions (A.S.D/A.S.C.) concept and the development of more sophisticated assessment tools has resulted in greater numbers of people being diagnosed. Information regarding increased prevalence of people with

learning disabilities and A.S.D/A.S.C. in the U.K. is outlined in the Prevalence section of this strategy. Increased numbers of assessments and diagnosis of children and adults with A.S.D/A.S.C. has resulted in greater numbers of people availing of services which, in turn, has helped shape U.K. Government policy on the provision of services.

'Better Services for People with Autistic Spectrum Disorder' (22) is a U.K. policy document which states that: -

- People should have fair access to support services and, if access is refused, reasons should be given.
- Services should be local so that people can remain close to their family/support networks.
- People should be included in society and the community in which they live.
- People should get an assessment from appropriately qualified professionals.
- People should be able to get the best service for them and to control the support they get.
- Everyone should be actively involved in planning their own support services.
- People with A.S.D/A.S.C. should have access to advocacy services.
- Families/carers should have a right to appropriate respite when they need it.
- Families should receive good information and their views/opinions should be taken into account.
- Families/carers have a right to an assessment of their own needs.
- Staff should be trained to meet the needs of the people they are supporting.
- Services need to be organised and delivered to meet the needs of people with A.S.D/A.S.C.
- Services should support people with A.S.D/A.S.C. into paid employment. Some services employ people with A.S.D/A.S.C.

In the Isle of Man, Children's Services, in partnership with the Department of Education and Health, provide assessment and diagnosis for children with A.S.D/A.S.C. Adults with A.S.D/A.S.C. can have access to a visiting Clinical Psychologist and Consultant Psychiatrist on the Island. There is no standing multi-disciplinary community disability team on the Island.

Adult Placement

Adult placement or shared lives schemes for people with learning disabilities is a means of providing person centred support to people who may find it extremely difficult or impossible to carry out daily functions/tasks and allows them to have a good quality of life. Adult placement can offer both long-term and short-term support depending on the person's needs and circumstances. It has been used to provide carers with some short-term respite or to provide people with a long-term placement in a family home. It is the responsibility of Social Services to assess the individual, organise the placement, provide carer training and monitor the placement. Carers are screened, trained and approved prior to registration. Every effort is made to match carers with the person who has the learning disability and trial placements are organised before placements are agreed. In the U.K., adult placement schemes are required to be registered with the Commission for Social Care Inspection and should comply with national minimum standards.

The Isle of Man operates a small temporary adult placement scheme which currently provides a service for two adults with learning disabilities. An experienced Social Worker has now been seconded to formulate policies, standards and a service framework to provide a more extensive and permanent adult placement scheme on the Island.

Transition - Supporting Young People

The Adult Disabilities Social Work Team, in conjunction with Children/Families Social Work Team, are committed to providing a person centred transition programme to support young people with learning disabilities to move into adulthood in the Isle of Man. The production of an Isle of Man Transition Report in 2011 (23) was a positive development in the planning the identification and transition of young people from children's to adult services. Transition reports are completed annually, with six monthly interim review meetings.

To further help young people to achieve their maximum potential, there is further work to be done on the: -

- Development of a revised protocol in the Isle of Man which designates the responsibilities of all services and providers for young people moving into adulthood.
- There should be clear and accessible information for young people to enable more effective person centred transition to take place.
- Better information and sharing of information for planning and commissioning of future services.

End of Life Care

The previous Isle of Man Learning Disabilities Strategy advocated a ‘cradle to grave approach’, in partnership with other agencies when providing services for older people with learning disabilities. End of life care helps people with progressive and life-threatening illnesses to have good end of life care. Identifying people’s needs early is beneficial in beginning/end of life planning. Early diagnosis allows more time to plan for the provision of support/care needs with and for the person in question.

Guidance regarding sharing of information and participation of the person with learning disabilities, who is approaching the end of their life, is contained in the 2011 National End of Life Care Programme (24). The development of an end of life care pathway reflects the need to work with the person (where possible), other professionals and services in making choices and planning end of life care. In short, the end of life care pathway is broken down into the following 6 steps: -

- Step 1** Discussions as the end of life approaches
- Step 2** Assessment, care planning and review
- Step 3** Coordination of care
- Step 4** Delivery of high quality services in different settings
- Step 5** Care in the last days of life
- Step 6** Care after death

Learning Disability Services in the Isle of Man should include the development of an end of life care pathway as one of its strategic priorities.

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Financial Resources

The Department of Social Care invested approximately £11,685,270 in 2011/12 to support adults with learning disabilities. This does not include funding for adults with learning disabilities in older people’s residential care and nursing homes. Health Services on the Isle of Man do not have an allocated budget for adults with learning disabilities. The Department of Social Care is responsible for specific funding of services for adults with learning disabilities, both on and off Island. Approximately, over 80% of the entire Department of Social Care revenue budget for 2011/12 (£11,685,000) was invested in on/off Island residential care. Almost two-thirds of total Department of Social Care revenue spending is currently allocated to statutory services, with 83% of this statutory funding going to fund residential care. Details of how this funding is allocated are set out in the table below: -

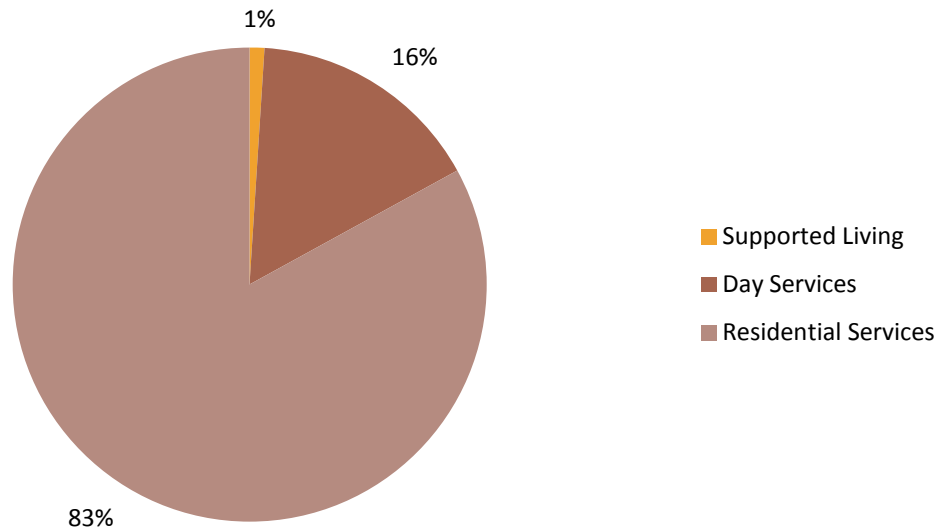
Fig.1

Service Area	No of People	Cost
DSC – Adult Services, Learning Disabilities – Allocated Budget	366 (181)	£7,358,72
Adult Learning Disabilities Specific Costs		
On-Island Spot Contracts	6	£80,250
Off-Island Spot Contracts	18	£1,677,800
• Client Travel		£25,000
<i>On-Island Contracts</i>		
• Autism Initiatives	49 (42 people)	£1,597,000
• Crossroads Care	39 (8 people)	£351,500
• Praxis	5 (5 people)	£531,000
• United Response (Advocacy)		£59,500
• Grant – Manx Gateway		£4,500
Total	483 (260)	£11,685,270

The total amount invested by the Department of Social Care in the revenue budget for 2011/12, divided by the number of individual people with learning disabilities using services funded directly by the Department of Social Care, equates to a spend of almost £45,000 per person. The total amount allocated to adults with learning disabilities constitutes to approximately 51% of the total Adult Social Services revenue budget.

A recent report (1) which reviewed the annual revenue budget allocated and spent on services provided directly by the Department of Social Care concluded that there was a very traditional spending profile, with 99% of spend being allocated to residential and day services and only 1% to supported living and supporting people in their own homes (see Fig.2).

Fig. 2



The report recommended ‘rebalancing the provision of social care will meet service users’ needs through an appropriate mix of services, will allow for increased demand for services and will be financially sustainable.’ A rebalancing of services towards more community-based care and support will reduce reliance on residential care and to increase community person centred supports. The aim is not to cut budgets but to use resources to give people more control and choice over purchasing the support they require.

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1. ‘The case for Change. Adult Social Services Transformation’. Tribal, April 2011

Benefits

The Isle of Man provides a range of benefits to adults with learning disabilities, including Disability Living Allowance, Mobility Allowance, Income Support and Attendance Allowance. In England, Putting People First (1) was introduced in 2009 to enable all people who need extra support to get good information about what is available to them, in order to help people live in their homes for longer and enable them to use mainstream services. It attempted to reform the way public services were funded, by increasing transparency and service user control, over how services were purchased. The introduction of personal budgets and in some cases direct payments to adults with learning disabilities, was part of Valuing People's personalisation agenda, to give people more choice and control over commissioning their own care and support. As of March 2012 there were 430,000 people (53% of users of community services in England) using personal budgets. In Scotland, nearly 4,400 out of 63,000 people availing of home care, were receiving a direct payment. However, the rate of increase in the numbers taking up direct payments in the last year has stalled, despite evidence of better outcomes (2).

Personal budgets are allocations of funding given to service users, after an assessment, which should be adequate to meet the person's needs. Service users may take their personal budget as a direct payment, or they may choose how their care needs are met and by whom and leave councils to organise/commission these services on their behalf. Direct payments are where service users decide how their care needs are met, either by employing people (personal assistants) or commission services themselves. In the U.K., Canada and other countries, this has led to the creation of a movement (In-Control U.K.) which lobbied for increased, self-directed, support to be incorporated into legislation. It is envisaged that, over the next five years, personal budgets will be available to everyone receiving services funded by UK councils, including those receiving residential care.

During the lifetime of this strategy it is proposed to: -

- Produce a benefit entitlement guide for adults with learning disabilities.
- There are likely to be developments relating to broader means testing for services over the coming months/years. This process will identify eligible need, determine the associated cost of appropriate care services and apply a financial assessment to determine the level of client contribution.

References	
1.	'Putting People First. A shared vision and commitment to the transformation of Adult Social Care'. 2009. H.M. Government
2.	www.communitycare.co.uk/direct-payments-personal-budgets (25 th July 2012)

Workforce Development

One of the policy objectives of Valuing People Now is that the workforce, across all public services, is given the training and support to promote their understanding of the values, rights and delivery of personalised services to adults with learning disabilities, including those people with complex needs. The implementation of the Adult Social Care Workforce Strategy in England (1) has helped to identify a need for the whole workforce (including personal assistants) to focus on the delivery of more preventive, more personalised and community based services. The strategy also addresses training requests and needs of both unpaid carers and service users. This strategy has six themes which underpin remodelling the delivery of adult social care. These include: -

- Recruitment/retention and career pathways
- Workforce development
- Workforce remodelling
- Leadership/management and commissioning skills
- Joint and integrated working
- Regulation and quality improvement

The transformation of Learning Disability Services, with the improved range choice of accommodation, personalised support, health care provision and access for people into work, in conjunction with increased demand for future services, has reflected a need for the workforce to become increasingly skilled to enable people with learning disabilities to live more independently in their own homes. As previously mentioned in this strategy, the growth of personal budgets and direct payments has led to an increased demand for personal assistants who are required to support people to live active and healthy lives in their community. The introduction of the Qualifications and Credit Framework (Q.C.F.) in England offered a new way of recognising skills and qualifications, by awarding credits for units completed right up to Masters Degree level, for staff working in Adult Social Care. Q.C.F. replaced N.V.Q.s in 2011, although N.V.Q. continues to be recognised but these are not now available for new registrations.

In the Isle of Man, staff working in Adult Social Care are provided with ongoing vocational development and training opportunities, including – mandatory training courses, N.V.Q., I.L.M. and Registered Managers Award. A key task of this strategy is to recommend changes in support and training for staff to equip them to deliver community/personalised

services, in keeping with the values and priorities contained in Valuing People Now. There should also be information, support and training made available to families and carers, based on feedback from the proposed introduction of carer's assessments on the Island.

References

1. 'Adult Social Care Workforce Strategy in England'. Department of Health 2009

Measuring Outcomes

The Adult Learning Disability Service currently collects information and produces quarterly key performance indicators (K.P.I.s) which measure such things as: -

- Number of person centred plans completed for individuals engaged with residential/day services (target two per annum).
- Number of staff supervisions per year (target four per annum).
- Number of staff who have completed annual appraisals (P.D.R.).
- Number of staff who have undergone work related training (target all staff to complete mandatory training, 50% completed N.V.Q. and all managers Registered Managers Award).
- Staff sickness (target 5%).

Performance of the Isle of Man Adult Learning Disabilities Service is monitored internally against the above set of indicators. Residential services are inspected by the Registrations and Inspections Unit based within the Department of Social Care. The Commission for Social Care does not operate within the jurisdiction.

Measuring outcomes should be linked to the four priority areas laid out in Valuing People Now – work, housing, health and personalisation. The successful implementation of this strategy will require a more comprehensive performance framework requiring the updating and extension of current information systems. The irreversible move towards greater personalised, inclusive and community orientated services will require more comprehensive data to monitor future performance. Data collected on housing/accommodation, work/employment, education and health will be required to measure this performance. As people with learning disabilities become increasingly involved in designing and commissioning their own services, it will become necessary to change the type of information collected and the methods used to collect it, i.e. a bigger role for people with learning disabilities and their families in shaping outcome measures.

The proposed Isle of Man Learning Disabilities Board, which will include representation from individuals with learning disabilities and carers, should produce a comprehensive performance and outcome framework. This framework should include national policy drivers, such as: -

- Increase the number of carers who have their needs assessed.
- Increase the number of adults involved with services (both statutory and Third Sector) on the Island.
- Increase the number of people with learning disabilities who are in paid employment.
- Increase the number of people with learning disabilities in supported living and supported housing as a proportion to people in residential care.
- Increase the numbers of people with learning disabilities who own/partially own their own properties.
- Increase the numbers of people with learning disabilities who are registered with a G.P. and attend their surgery for annual health checks.
- Monitor/measure the number of people engaged with Learning Disability Services who have a Health Action Plan.
- Extend local self advocacy forums for carers and adults with learning disabilities and include these groups in any future policy developments.

Reviewing this Strategy

This Five Year Strategy and Service Delivery Plan provide a basic framework for strategic planning, against which, progress can be measured. The focus will be on implementing the recommendations contained in this strategy and meeting the outcomes contained in the Service Delivery Plan. Outcomes in the Service Delivery Plan are broadly based on the four priorities identified in Valuing People Now. Recommendations and outcomes are committed to ensuring that adults with learning disabilities and their families/carers are supported to maximise choice and control over how they are supported, in keeping with the following international and national policy drivers: -

- Valuing People Now
- Same As You
- Isle of Man Social Services Act
- Health and Social Care Act 2010
- Putting People First
- Valuing Employment Now
- Isle of Man Carers Strategy
- Healthcare for People with Disabilities
- Mansell Report
- No Secrets
- Better Services for People with Autism Spectrum Disorder
- National End of Life Care Programme
- Isle of Man Regulation of Care Bill
- A review of the Scope of Government in the Isle of Man
- Adult Social Care Workforce Strategy in England

Recommendations

The recommendations contained in this Five Year Strategy for Adults with Learning Disabilities are directly linked to the outcomes catalogued in the five classifications contained in the Service Delivery Plan. Safeguarding has been added to the four identified priority areas and allotted a separate section within the service delivery plan in response to recent developments in England. These recommendations and outcomes reflect current best practice and guidance contained in national and international policies. The main aim of this strategy is to support adults with a learning disability to be active citizens, within their own community, rather than have statutory services replace their individual support network.

The current design, funding and mix of social care services are addressed in this strategy. The overarching priorities, direction of travel and proposed outcomes, contained in the Delivery Plan, should help ensure more effective commissioning of services that best support adults with learning disabilities and their families on the Island. It will be the function of this commissioning strategy to determine the future balance of services provided by the statutory and Third Sectors.

1. To develop and introduce eligibility criteria for access to Adult Learning Disability Services funded by the Department of Social Care which are consistent with the Department's Fair Access to Care Services (FACS).
2. To introduce the right to a carer's assessment under Part 3 of the proposed Social Services Act and plan for inevitable increase in assessment/review activity as applied across the Department.
3. To create a local Learning Disabilities Partnership Board with four sub-groups to ensure that the four priorities contained in this strategy are put into action. Separate Safeguarding Board proposals have been agreed by the Department - to be introduced in the future.
4. The local needs and priorities identified by the Learning Disabilities Partnership Board and sub-groups will contribute to the formulation of future commissioning strategies.
5. Implementation of the Carers Charter currently going through consultation process in the Isle of Man.
6. Upgrade the quality of demographic information collected by all Learning Disability Services on the Island to ensure better planning and commissioning of evidence based services.

7. To incorporate local prevalence data in the future planning and commissioning of services for the increasing numbers of children approaching adulthood with multiple/profound needs.
8. Plan and work in partnership with other agencies to provide accommodation/housing to meet the needs of increasing numbers of older people with learning disabilities.
9. Plan and commission services to support increasing numbers of adults diagnosed with A.S.D/A.S.C.
10. Collect and collate service user opinions, feedback and complaints regarding the services they receive/do not receive.
11. To work in partnership with Older People's Mental Health Service to introduce the offer of screening for dementia for all adults with Down's Syndrome.
12. To work with the increasing number of older carers, who are supporting adults with learning disabilities in the family home, to contribute to planning and developing personalised future services for their daughter/son.
13. To commission, in partnership with other agencies, a range of preventative community services for adults with learning disabilities, who have been assessed as having low needs under FACS, to maintain their existing natural support networks and avoid entry into residential care services.
14. In partnership with other Government departments, increase the number of people with learning disabilities in real paid jobs.
15. In conjunction with the relevant Government departments, introduce a pathway to work for young people with learning disabilities leaving school/college.
16. To increase supported employment options through the development of the proposed restructured and independent Social Firm.
17. To review the present structure and referral protocol of the Social Firm to promote independence and ease of access.
18. Statutory and Third Sector services to increase the mix of employment, further education and community support opportunities for adults with learning disabilities.
19. Increase daytime opportunities for people with profound/multiple learning disabilities.
20. Assess the needs of adults currently in Department of Social Care residential services, with assistance from the advocacy service, and explore alternative models of accommodation and support.
21. Determine the size, scope and structure of services operated by the Department of Social Care and incorporate outcome into future commissioning strategy.
22. To create greater independence and choice of accommodation and support for adults with learning disabilities by rebalancing the proportion of residential care to supported

living/supported housing/home ownership and adult placement in keeping with the principles laid down in Valuing People.

23. To develop and expand the range of accommodation and support options by re-appropriating surplus monies from the proposed reconfiguration of residential services.
24. Develop a transition pathway for young people with learning disabilities and A.S.D. who wish to move on from their family home to their own home.
25. Statutory, Third Sector and Voluntary Organisations to provide increased floating and extra care options for people assessed with low/medium level needs living in their own homes.
26. Develop home ownership options in the Isle of Man based on existing U.K. models. To work in partnership with Third Sector who can undertake the role of social landlord regulated by the Department.
27. Develop and extend a modern range of respite/short-term breaks service currently provided by the Department of Social Care, Crossroads Care and Autism Initiatives in conjunction with service users and their families/carers. Fully implement recommendations of 2008 Report on the Development of Respite Services across the Department of Social Care and Third Sector.
28. Evaluate the effectiveness of the G.P. practice register for people with learning disabilities since been introduced on the Island.
29. Monitor/Evaluate health care performance indicators (including waiting times) for all people with learning disabilities and A.S.D/ASC. involved with Learning Disability Services delivered by both the Department of Social Care and the Third Sector.
30. Sub-group of proposed Learning Disabilities Partnership Board to collect and analyse health and social care data in accordance with recommendations contained in the Right Care Project.
31. Formulate a programme for improving health promotion advice and literature for people with learning disabilities and their families/carers.
32. Deliver equality training for front line health and social care staff.
33. Develop a specific pathway, in conjunction with Older People's Mental Health Services, for people with Down's Syndrome at risk of developing dementia.
34. Develop a care pathway for delivery of palliative care and end of life care for adults with learning disabilities.
35. Monitor and evaluate effectiveness of the current guidelines for 'Admission to In-Patient Service of a Service User with Mental Health & Learning Disability Dual Diagnosis from Residential Services'.
36. Establish an Adult Safeguarding Board as already proposed by the Department.

37. To establish a regulatory and inspection framework for supported living services as envisaged by the Registration and Inspectorate Team.
38. To support United Response or alternate agency to develop more self and peer advocacy groups across the Island.
39. To provide greater advocacy for people with complex and multiple needs especially around issues such as safeguarding, person centred planning, training and employment.
40. To provide greater access to personalised day time activities and supported paid/unpaid employment for people with multiple/profound needs.
41. Develop evidence based practice and outcomes framework for services providing support for people with challenging behaviours to demonstrate progress and cost-effectiveness as recommended by the Mansell Report.
42. To continue to provide specialist support and training for staff providing services to adults with challenging behaviours.
43. To expand personalised local services for adults with A.S.D/ASC. in keeping with the National Autism Strategy.
44. To revise the transition protocol for young people making the move to adult services.
45. Provide more accessible/better information for adults with learning disabilities and in particular for young people approaching transition and their families.
46. Analyse and make decisions regarding the current balance of services both on and off-Island. Each service contract should be analysed and benchmarked in the context of the principles and priorities set out in Valuing People and other policy directives.
47. Ensure adults with learning disabilities are making best use of their own social capital to enhance their independence and live more fulfilling lives.
48. Greater partnership working with other government agencies and the Third Sector in the development of housing and support services for people with learning disabilities and A.S.D/ASC.
49. Produce an easy read benefit entitlement guide for adults with learning disabilities and their families.
50. To introduce themes contained in the Adult Social Care Workforce Strategy in England across the Department of Social Care and Third Sector on the Island.
51. Introduce a comprehensive performance and outcome framework based on national policy drivers and identified in this strategy.
52. The actions contained in the service delivery plan should be reviewed by the proposed Learning Disabilities Partnership Board annually commencing January 2014.

END OF CONSULTATION DOCUMENT



This document can be provided in large print on request

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**Isle of Man
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