

Looking to the future

A review of Renfrewshire Health and Social Care Partnership's
Day and Respite Services

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February 2019

(Word cloud created from the voices of people with a learning disability in Renfrewshire in 2018)

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LOOKING TO THE FUTURE: THE REPORT

Introduction

In August 2018, Renfrewshire Health and Social Care Partnership, commissioned Paradigm to support the review of learning disability day and respite services.

This report explains how we facilitated the review. It shares our reflections and recommendations developed in response to national policy and the thoughts of the people we met: people with a learning disability, family and carers and staff from a range of services.

People with a learning disability told us how important the services are to them, how they meet their friends there, and how much they like the staff.

We also met people with a learning disability who talked of their desire for more - people who would like to go out in the evenings, to have a job, to have a pet, to leave home and to find a boy/girlfriend.

'It's hard to think about the future. I want to be happy, enjoy my life and be able to have friends...I'd like a house and to look after my pets.'

Person with a learning disability

We heard from **family and carers** who dedicate so much of their lives to ensuring the person they love has a good life. Some family and carers advocated for keeping the more traditional services that they knew well and were happy with, whilst some family and carers, often the younger parents, were keen to explore more fluid versions of support as their sons and daughters, particularly when leaving school.

'We want to work together to get the best possible for our sons and daughters in a culture of openness, transparency and honesty.'

Carer

Staff talked of their passion for their work, for ensuring the people they support live good lives and their pride in the improvements to services over the past few years. We also spoke to staff who are full of ideas and determination to keep moving forward to improve the range of support and opportunities offered.

*'How can we (those we support,
carers and staff) work together to develop new,
non-traditional, ideas?'*

Staff

Paradigm believe this is an exciting time when all those engaged with the Renfrewshire Health and Social Care Partnership services can step forward together to ensure more personalised, community focused, support and opportunities for people with a learning disability in the future.



The Aims of this Review

The overarching purpose of the review was to assess all aspects of Renfrewshire's learning disability day and respite services to ensure they are modern, flexible, outcomes focused; financially efficient and 'fit for the future'.

The review set out to consider changing trends, demographics, demands, local and national policy drivers and the range of stakeholder views.

The current range of day and respite services are recognised as being of good quality by the Care Inspectorate and many people and families highly value them.

There are several policy drivers and standards which underpin the requirement for the review, they are as follows:

- The Same as You? (2000)
- The "Keys to Life" (2013)
- Social Care (Self-Directed Support) (Scotland) Act 2013
- Talking Points – A Personal Outcomes Approach
- A Fairer Scotland for Disabled People 2016

- Scottish Autism Strategy (2011)
- National Health and Well Being Outcomes
- Regulation of Care (Scotland) Act – National Care Standards
- National Involvement Network – Charter for Involvement
- Carers (Scotland) Act 2016 (2018)
- Renfrewshire Health and Social Care Partnership – Strategic Plan 2016-19

The '*Terms of Reference*' for the review highlighted that some people do not want to consider the type of services currently available. For example, younger people with a learning disability have different expectations about how their support may be shaped in the future beyond attendance at a traditional building-based day service.

The review was met by family and carers with concern and suspicion that the aim was to close day centres and make cuts. Renfrewshire Health and Social Care Partnership has provided consistent reassurance that this was never the intention and much work has been done to ensure all who wanted to, could contribute to the review, could do so.

Paradigm was commissioned to work in co-production with people with a learning disability, their family and carers, as well as the Health and Social Care Partnership and wider stakeholders.

Scope of the Review

The review focused on the day and respite services provided by Renfrewshire Health and Social Care Partnership, which Paradigm have grouped into headings to best describe what they do:

- **Core Day Services:** Anchor Centre, The Mirin and Milldale
- **Community Support Services:** Community Networks and Flexicare
- **Learning Disability/Autism Specific Services:** Gateway Intensive Support and Autism Connections
- **Respite and Short Breaks:** Weavers Linn
-

The services within the review have 5 managers and are externally coordinated by the Operational Manager. All services excluding Autism

Connections and Flexicare are registered and inspected by the Care Inspectorate under the Regulation of Care (Scotland) Act¹.

West Lane Gardens and Whitehaugh Day Services are delivered by Capability Scotland and therefore they are not included in this review. However, due to Capability Scotland's planned withdrawal in April 2019, those who access these services were invited to make their voices heard as part of this review.

The Paradigm Team

Paradigm works across the UK with support staff, people with a learning disability, family members, providers, commissioners and regulators to develop thinking and support that focuses on good 'ordinary lives'.

Our work ranges from deep service reviews and to creating the REACH Standards in Supported Living, facilitating training, to creating and facilitating The Gr8 Support Movement (for Support Workers) that reaches out to over 10,000 support staff in the UK.

For this review we brought a range of national and local experience and knowledge. Working alongside 'Values into Action Scotland' who promote the rights and equality of people with a learning disability and/or autism. The team included six people: two of whom have a learning disability and one with lived experience as a Carer.



¹ <http://www.legislation.gov.uk/asp/2001/8/contents>

How Paradigm facilitated the Review

Paradigm are passionate about co-production and facilitate in a highly interactive and engaging way.

“Co-production is a way for those who run public services and those who use them, to come together to make the most their own skills and ideas to improve how services work.”

Scottish Co-production Network

Consequently, at the heart of this review, was the commitment to work with people with a learning disability, family and carers, staff, senior management team and other stakeholders to explore what people value about the day and respite services and what they would like to see in the future.

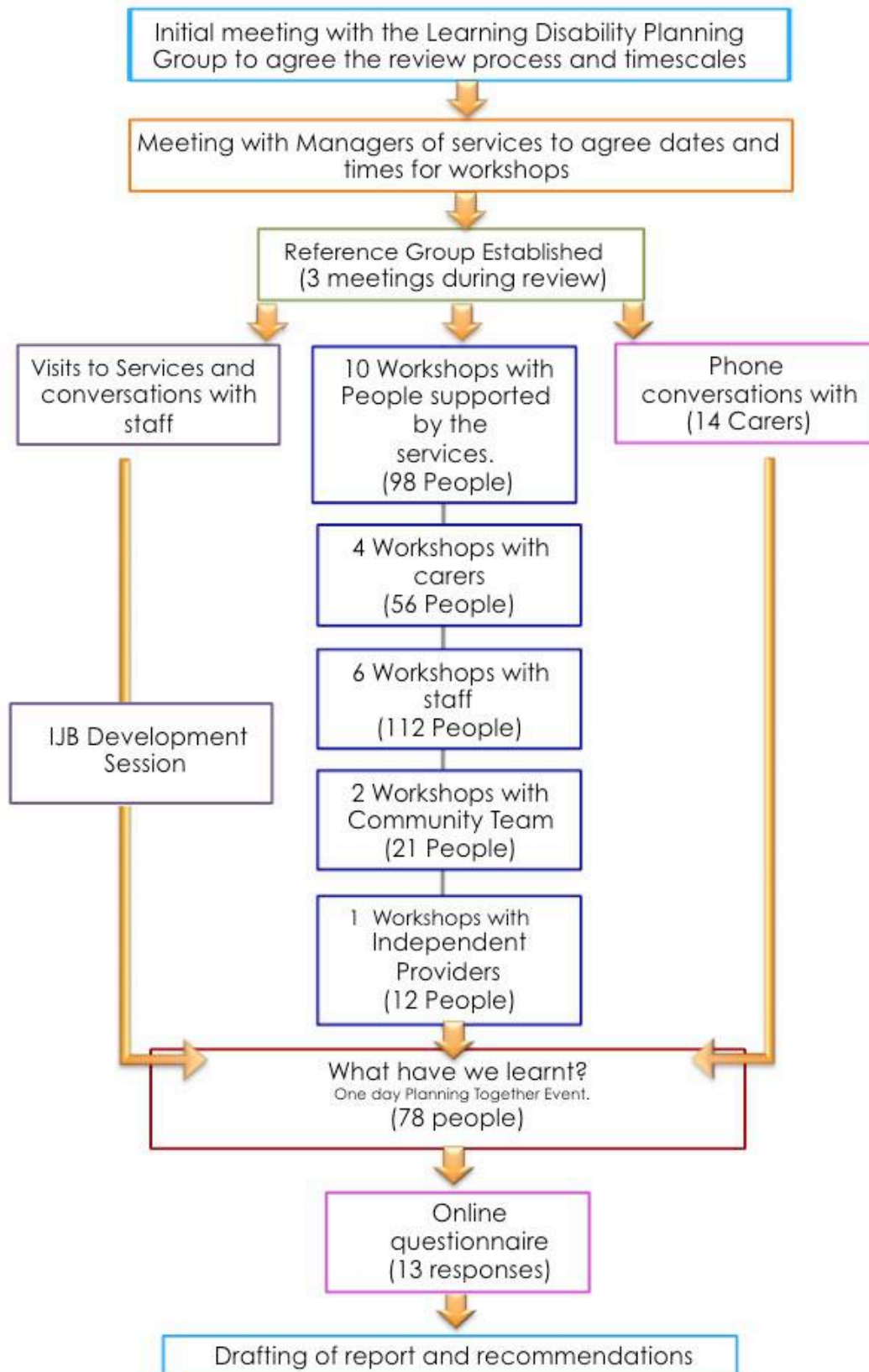
A variety of spaces were created for people's voices to be heard and for conversations to be held from one-to-one interviews to workshop events. Perhaps most importantly, Paradigm enabled people to have honest, sometimes difficult, exploratory and brave conversations together. This allowed people to ask questions they had never asked before and express their anxieties and their desires.

We are thankful to all those who took part and hope that they will see from this report that their voices have been heard and represented. Paradigm view co-production as:

“A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities.

National Co-Production of Critical Friends Group

Figure 1: The Review Process:

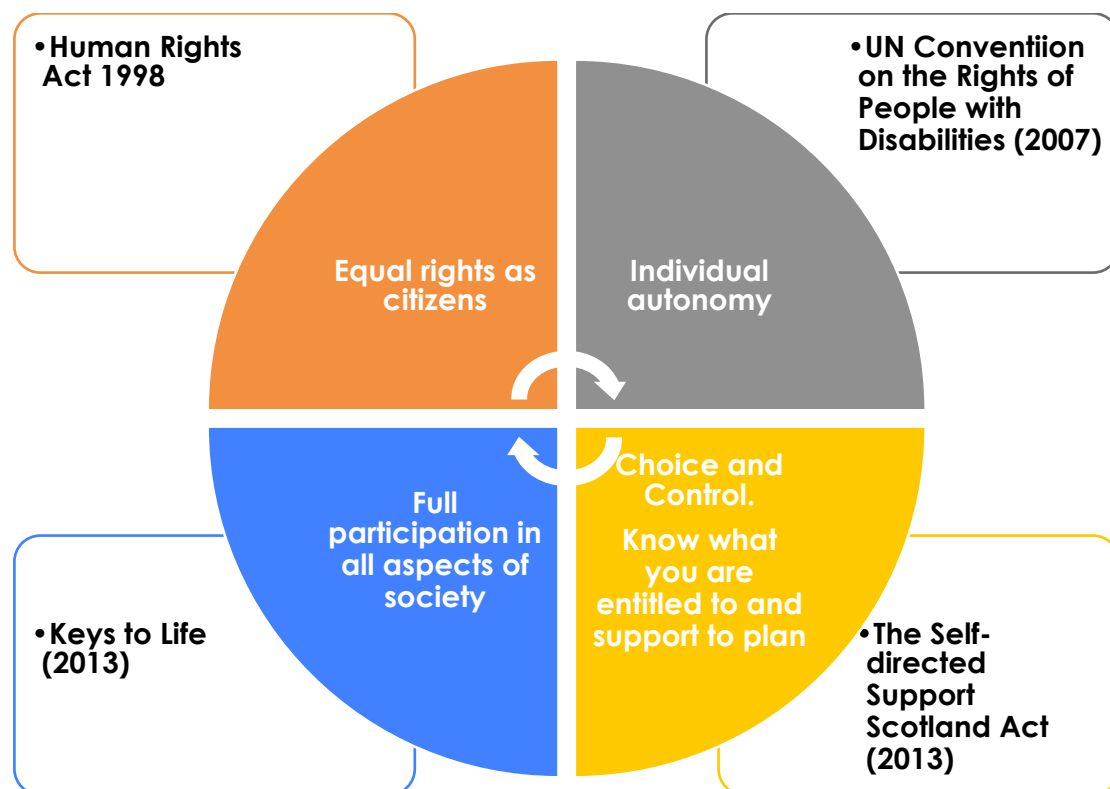


The National context

1. Current legislation & policy: promoting a human rights based approach

Over the last 20 years there has been recognition that inequality and discrimination has a significant impact in determining the quality of life for people who have a disability. People with disabilities tend to experience poorer outcomes across many aspects of life when compared to people who do not have a disability – for example, health, financial security, education, relationships, and employment². This has led to significant international and national developments. Legislation and strategies have evolved, all of which have at their heart an intent to strengthen the rights of people with disabilities to improve their quality of life and life opportunities.

Fig 2: Key international & Scottish legislation & policy framework



²Scottish Learning Disability Observatory: <https://www.sldo.ac.uk/>

Together these frameworks provide a fundamental and consistent guide for planning and delivering support that underpin the way forward for all who directly support people including the wider community.

The Human Rights Act 1998³ places a duty on public authorities to ensure that all actions and decisions that they make take rights into account. For example:

- Article 3 – freedom from torture/inhuman/ degrading treatment – is key for people with learning disabilities. The right to receive care and support that is dignified and respectful.
- Article 8 – a right to respect for private and family life – people with learning disabilities have a right to live their life privately, to enjoy family relationships (including the right to live with their own family), and to enjoy their home peacefully without interference from public authorities.
- Article 12 – the right to marry – means that people with learning disabilities have the right to marry and to start a family, just like everybody else.
- Article 14 – protection from discrimination – requires all rights and freedoms set out in the Act to be applied without discrimination (direct or indirect). In other words, people with learning disabilities should not be stopped from enjoying any of the other rights in the Act because of their disability.

The United Nations Convention on the Rights of Persons with Disabilities⁴ was formerly ratified by the UK Government 2009. Smith⁵ explains that this was the first human rights treaty to be adopted by all members of The United Nations in the 21st Century.

'...the dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for too long.'

UN Secretary General Kofi Annan

The Convention on the Rights of People with Disabilities and the Human Rights Act helped to provide the momentum for local strategies, to translate the principles into action which would enhance, improve and protect the experiences of people who have a disability.

³ <https://www.legislation.gov.uk/ukpga/1998/42/contents>

⁴ United Nations Convention on the Rights of Persons with Disabilities (2007)

⁵ Sam Smith, *Human Rights in Social Care – Putting rights into practice*, Dunedin, 2018

'Keys to Life'⁶ is the national strategy for people with a learning disability. The strategy was launched with a powerful vision that we all work to a future where:

'all citizens of Scotland live longer, healthier lives; are supported to participate fully in all aspects of society; prosper as individuals and are valued contributors to a fair and equal Scotland.'

Keys to Life

A review of the strategy in 2015 led defined four strategic outcomes:

- Health
- Choice and Control
- Independence and
- Active Citizenship

It should be noted 'Keys to Life' is currently being refreshed. We understand this will include recommendations based on good practice which has been emerging across the UK:

- asset based approach to citizenship
- a focus on young people, including early years
- policy shaped around lives, not lives shaped around policy
- key themes of well-being, living, working and learning

'The Self-directed Support Scotland Act'⁷ introduced a powerful change to the way people who are eligible for support from Health and Social Care should be involved in planning their care and support and in how this is purchased /commissioned.

At the heart of the Self-directed Support Act (SDS) is the desire to work to a future where:

- Disabled people have the same freedom and choices as others at home, at work or in the community.
- People get the kind of support they want, where and when they want it.
- People get support at the right time, before a crisis or emergency happens.

⁶ Keys to Life, 2013 – <https://keystolive.info/>

⁷ The Self-directed Support Scotland Act (2013), <http://www.legislation.gov.uk/asp/2013/1/contents/enacted>

In November 2018 the report 'Coming Home'⁸ was published. The report makes several key recommendations around strengthening Social Care Services in the community. These are:

- supporting family and carers
- improving the commissioning, planning of services and housing
- developing the social care workforce to ensure local support is available.

'The Scottish Government wants to support Health and Social Care Partnerships to find alternatives to out-of-area placements, and to eradicate delayed discharge for people with a learning disability.'

Coming Home 2018

These international and national laws and strategies highlight the need to continue to develop support in Renfrewshire that meets the fundamental expectations and rights of all.

2. The move away from building-based services

The 'Keys to Life' strategy acknowledges the serious impact of the economic downturn across Scotland and the challenges and complexities in supporting people to achieve inclusion in an era of dwindling resources.

At the same time, even when public finances are under considerable pressure, there has been, until recently, across the UK a gradual decline in people attending building-based day centres and an increase in people accessing alternative day opportunities⁹.

Reports on the impact of the shift away from building-based day services highlight both the positive and negative experiences. For example, Mencap's 'Stuck at Home' report¹⁰ suggests people 'can be left socially isolated, bored and lonely, and important friendships and support networks are lost.' The report recognises that the 'modernisation' of day services is essential and cautions that it must not be driven by cuts, but a genuine desire to work with people who use the services, families and staff to explore how to increase choice and improve the quality of life for all.

There are projects across the UK exploring how people with a learning

⁸ [Coming Home](#) (2018) Scottish Government

⁹ Hatton, C. 'Day and home care for adults with learning disabilities across the UK' (Tizard 2017)

¹⁰ Hall and McGarrol, (2013), *Stuck at Home*. MENCAP

disability can be supported beyond building-based day services, to help prevent isolation. One example is 'The 'Self Build Social Care Project' 2016¹¹ which recognises people often struggle to connect with their friends when building-based support is not available, for example, traveling to a friend. The research team, which includes people with a learning disability, is exploring how to create new forms of community-based peer-led support.

It should be noted that people with a profound and multiple learning disability are less visible in research. Whilst more and more people are being supported via Self-directed Support to create individually tailored support, many areas offer continue to offer a specific, often building-based services for people with a profound and multiple learning disability. If purpose-built buildings are required then the location, appearance and atmosphere need to be considered to ensure an inclusive community resource.

In order for people with a profound and multiple learning disability to be less reliant on building-based services and more included in their community, there must be an increase in 'Changing Places'¹² where people can have their personal and intimate care needs met safely and with dignity.

3. Employment matters

The 'Keys to Life' strategy recognises the importance of employment in the Active Citizenship outcome, encouraging services to develop volunteering and employment opportunities for people with a learning disability. In addition to this being good for the individuals in terms of quality of life and active citizenship, Beyer reported¹³ on significant cost savings when people gain employment and reduce their reliance on services.

It is important to note that employment support is most successful when developed in partnership with other teams, for example, Economic Development and the wider community.

4. Short breaks

The Shared Care Scotland report¹⁴ suggests that in recent years people with personal budgets are choosing different forms of respite as the use of

¹¹ Power, A. Bartlett, R and Hall, E. 'Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity.' *Journal of Intellectual Disabilities* 1 -11 (2016)

¹² www.changing-places.org

¹³ Beyer, S. 'An evaluation of the outcomes of supported employment in North Lanarkshire' Cardiff University (2007)

¹⁴ Shared Care. 'Analysis of Respite Data' (2015)

building-based respite has reduced. The importance of short breaks is now clearly understood and the report urges the government to remain vigilant to any disinvestment in the local respite offer and to support further efforts to improve provision so that family and carers, wherever they live, can achieve a life outside of caring.

'Short breaks are essential in supporting family and carers to maintain the caring relationship.'

'Keys to Life'

5. Examples of good practice around the UK

All around the UK, there are examples of organisations creating opportunities for people with a learning disability to have more flexible and innovative 'ordinary life' support that encourages independence and inclusion in line with national policy drivers.

In the current climate and to achieve the vision of 'Keys to Life', there is a need to think creatively and to learn with and from others to deliver the best support and opportunities possible.

Within the section 'The Voices and ideas of local people', we give some examples of good practice from around the UK. Here is one example:

Gig Buddies

'Gig Buddies' is a project that is part of the charity 'Stay Up Late'. They match people with a learning disability up with a volunteer who have the same passions, such as music or dance, so that they go out together each month.

See: www.stayuplate.org

Where Renfrewshire is Now

Renfrewshire profile

The National Records of Scotland estimated the population of Renfrewshire in 2017 as just under 177,000 people, with more women than men.

Renfrewshire Health & Social Care Partnership deliver adult social care services and all community health services for adults and children in the Renfrewshire area.

In 2018 the 'Scottish Commission for Learning Disability'¹⁵ published their annual report 'Learning Disability Statistics Scotland' which reports statistics about adults with a learning disability who were known to Scottish local authorities between 2017 – 2018. It is these statistics as well as local data that have informed this report.

¹⁵ <https://www.sclld.org.uk/2018-report/>



Statistics on people with a Learning Disability in Renfrewshire

National data reports that:

- in 2018 there were 23,446 adults known to local authorities across Scotland. This equates to 5.2 people with a learning disability per 1000 people in the general population.
- in Renfrewshire there were 692 adults known, which equates to 4.7 people with a learning disability per 1000 people.
- of these 692 adults 39.6% live with a relative or carer compared to 30.3% nationally.
- 335 adults currently access Renfrewshire Health and Social Care Partnership day services. This represents 48.4% of the Renfrewshire population of adults with a learning disability. The national average of people attending day services is 17.3%.

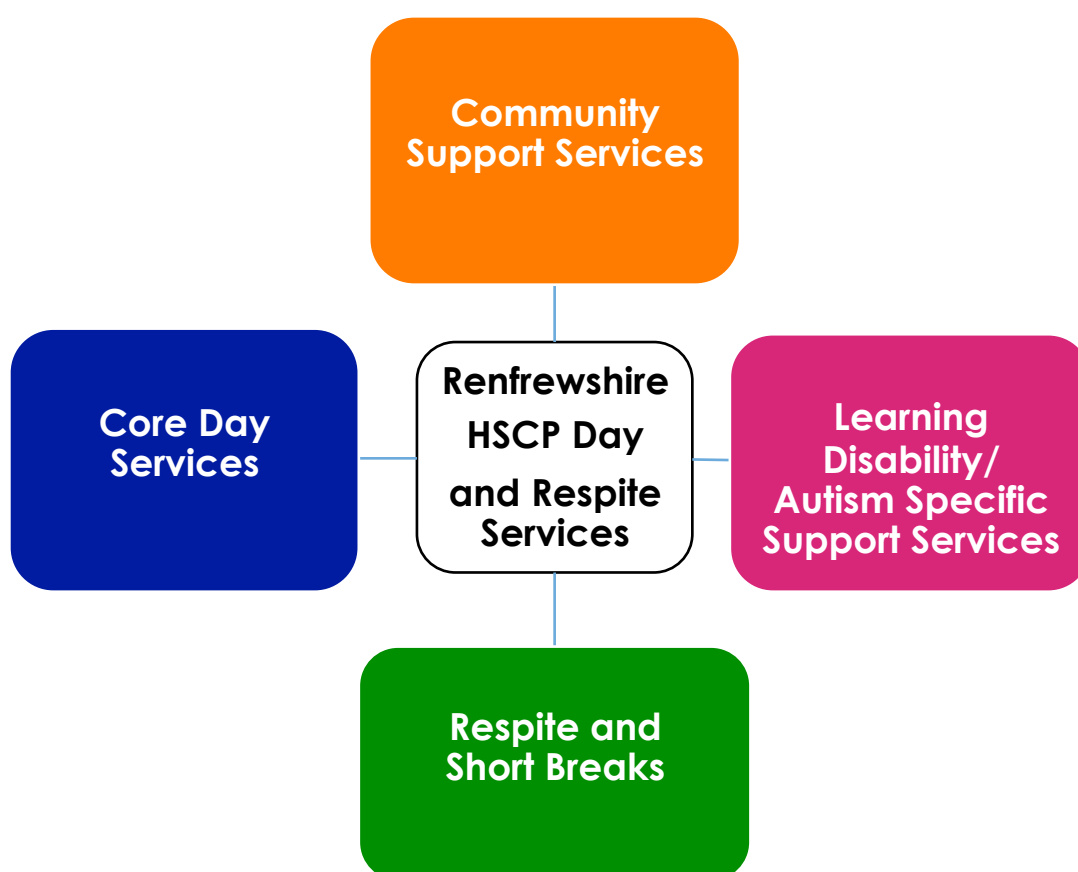
Local data reports that:

- 119 people are offered respite at Weavers Linn each year.
- 90% of those accessing the day services receive support to travel to and from the services.
- there is a fairly even gender spread across the services; 56% males & 44% females. This changes within Gateway with 81% of the 16 adults attending being male which is in keeping with the current males: female ratios for individuals with autism.
- the average age of an adult attending day services is 40 with age ranging from 18 – 75 years old (6 individuals aged 71+). There is a noticeable difference within Gateway where the average is 23 years old.
- 65% of the adults supported in the services under review live in their family home.
- there are 92 children (8 years of age and over) with a learning disability known in Renfrewshire. They will move into adulthood between 2019 and 2025. 62 have complex needs.

Renfrewshire's current services

The review focused on the day and respite services provided by Renfrewshire Health and Social Care Partnership. We have grouped the services within the scope of the review into categories that better explain the purpose of the service.

Figure 3: Renfrewshire day and respite services



Core Day Services

The Anchor Centre:

The Anchor Centre offers 48 spaces per day and is open 5 days a week to people with a profound to severe learning disability with associated complex health conditions and additional needs; mobility, sensory, autism, epilepsy etc, with the aim of developing their skills, offering skilled support, including

health support.

It is important to note that the Anchor Centre has a service specifically for people with a learning disability and autism. This is for those who do not require the support offered at Gateway Intensive Support Services. The building was redesigned in 2017 to offer more flexible space for both group and individual support with a hydro-pool, a sensory room and a multi-purpose hall.

Between April and December 18, the Anchor Centre had an average daily allocation rate of 81% (39 of 48 places being allocated). The average attendance rate is 94%. The centre currently supports 49 individuals.

The Mirin and Milldale

The Mirin and Milldale are sister day services and have the capacity to support 150 people a day and are open 5 days per week to those who have a severe to moderate learning disability and associated conditions i.e. autism, mobility, sensory, epilepsy needs.

Both aim to provide a positive environment for the development and maintenance of an individual's skills. There are a range of onsite facilities include a training kitchen, computer & interactive facilities, group rooms, music room, sensory room, art room, & personal care facilities are also available.

The Milldale Service is co-located with the On-X Leisure Centre, in Linwood providing support to up to 75 people a day and is open 5 days a week. Between April – December 2018, Milldale had an average daily allocation rate of 97% (73 of 75 places were allocated). Of the places allocated the average attendance rate was 86% (63). The centre currently supports 83 individuals.

The Mirin is co-located with the Lagoon Leisure Centre in Paisley, providing support to up to 75 people a day and is open 5 days a week. Between April – December 2018, the Mirin had an average daily allocation rate of 81% (61 of 75 places are allocated). Of the places allocated the average attendance rate was 86% (53). The centre currently supports 91 individuals.

Community Support Services

Community Networks

Community Networks offers flexible community-based alternative to the traditional day service model, for up to 25 people. The service is open 5 days a week, with individuals able to access support for up to 3 days a week. It is based within Spinners Gate, Paisley.

The service provides an integrated, community-based activities programme for individuals who can travel independently. The aim of the service is to ensure individuals are equipped with the appropriate skills and knowledge to lead a healthy and safe lifestyle and reduce crisis.

Between April – December 2018, Community Networks had an average daily allocation rate of 84% (21 of 25 are allocated). Of the places allocated the average attendance rate was 95%. The service currently supports 48 individuals.

Flexicare

The service was developed as an Urban Aid Project in 1989 and went on to receive core funding. The main aim of the service is to provide support to enable individuals, aged 14+ with learning disabilities to enhance their social and leisure lives within their local communities, this includes evenings. This is achieved this by recruiting and training a network of over 100 volunteers and sessional workers who provide support to individuals or within group settings.

Learning Disability/Autism Specific Support and Services

Gateway Intensive Support Services

The service is based within Spinners Gate Resource Centre, providing an specific service for people with a learning disability. The service is open 5-days a week. All people supported this service attend 5 days a week. It has a 1:1 staff/service user ratio with an emphasis placed on staff trained in autism and related therapeutic approaches. The overarching approach used within

Gateway is the S.P.E.L.L approach. This approach embeds all other strategies, interventions, policies etc. carried out within the service.

So far in 2018/19, Gateway Intensive Support Services has an average daily allocation rate of 95% (16 of 17 places are allocated). Of the places allocated the average attendance rate was 100%. The service currently supports 18 individuals.

Autism Connections

Autism Connections is a service developed in May 2016 and based within the Spinners Gate Resource Centre. The small staff team of health and social care practitioners provide support, with a five-tiered offer, to all services to promote a skilled and competent workforce in the provision of services to adults with a learning disability and autism in line with the National and local Autism Strategies.

Respite/Short Break Services

Weavers Linn

Weavers Linn is a modern purpose built 10 ensuite rooms residential respite service providing periods of respite to adults across the full spectrum of need including adults with complex health needs and adults with complex autism.

The facility is at capacity, and there is a lack of equity in the allocation of nights, as many people with the similar needs receive differing allocations. This in part is due to availability of respite at the point of assessment.



The Voices and Ideas of Local People

Throughout Paradigm's engagement and deep listening to over 300 people, we heard people share their ideas of how they would like to see Renfrewshire Health and Social Care Partnership day and respite services evolve in the coming years.

Here we share the ideas from the full range of people who engaged in the review. We also give illustrations of good practice, from elsewhere in the UK, in response to people's ideas for the future.

1. People with a learning disability

The people with a learning disability who contributed to the review came from across the services.

Many people told us they were happy with the support they receive and don't want any change. Others clearly talked about wanting things to be different.

We encountered a powerful response to the question 'What would you like in the future?' People started to talk about life, not services, about the ordinary things that make a full life. Some people said that they have been doing the same sort of things for a long time. People said they want to be with people they like, doing things they enjoy, at the time and place that is right for them.

"What would I like in the future? Independence I think."

Person with a learning disability

"I would like to stay home some days, but I can't, there's no support."

Person with a learning disability

People told us that friendship is one of the most important aspects of, both the day and respite services. For those who do not travel independently, the services are the only place they can see friends. Those who are able to travel independently really value meeting friends at Flexicare and Community Networks.

"I like coming to the centre. I like being with my friends."

Person with a learning disability

Many people talked about how much they would like a partner, to fall in love, to get married and have their own family. The small discussions that started in the workshops highlighted how much people want to talk about love, sex and relationships. People would really welcome the chance to do so.

People talked about how much they enjoyed volunteering. A small number of people mentioned the desire to work and when they raised the idea with their peers, more people showed interest.

A number of people said how much they enjoyed being on 'Client/User' Committees in the services and being part of making decisions. Some people had really enjoyed Participation and the National Involvement Network events.¹⁶

Some people explained that travelling on the Maxi buses to and from the services is a good time to catch up with their friends and they have no desire for this to change. Others said they do not like the time they spend on the Maxi buses, as the buses are big and the journeys can take a long time. People don't like it when the transport is late and they miss the start of sessions. People talked about the desire to learn to travel on their own or with support. They were not sure how this would be possible but wanted to talk about it.

People talked about their desire to have their own home. At every workshop, people asked if this would be possible.

The combined voices of the people with a learning disability we met further strengthened the voices of thousands of people across the UK and beyond

¹⁶ <https://arcscotland.org.uk/involvement/national-involvement-network/>

who have, for decades, expressed similar desires. Desires to live a good ordinary life. To do and achieve things that many of us take for granted.

'The good stories we hear from people who are getting more of what they want from life, tell us that MUCH more can be achieved when individuals get the RIGHT support to find something better for themselves. Good allies in the journey to an ordinary life learn how better to assist people to have the valued experiences (respect, self-direction, belonging and contributing), which other citizens enjoy.' David Towell¹⁷

Ideas for the future from People with a Learning Disability

Friendship

People would like more opportunities to meet with their friends and make new friends, this includes at evenings and weekends. People said they would like to visit their friends at their houses and some said they would like sleepovers.

More chances to have our say

People would like more opportunities to be involved in decision making and to be part of local Participation and regional National Involvement Network events.

More Respite/Holidays

The time spent with friends at Weavers Linn was a highlight for many and they would like the opportunity to go there more often and to go on holiday with their friends with the support they require.

Volunteering and Jobs

Many people talked about how much they wanted to volunteer and would like support to do this and find a job.

Finding a partner

Run some courses and offer support for people to understand more about love, sex and relationships. Help people find ways of meeting potential partners.

More choices and community activities

¹⁷ <https://www.centreforwelfarereform.org/library/by-az/pathfinders-review-2.html>

Some people said they would like more choices of things to do during the day and evening in the community rather than in the a centre.

My own home and pet

People would like to have their own home. For some this includes having a pet.

Learning to travel

Some people want to learn to travel more independently.

Good practice examples from around the UK

Travelmate (HAIL)

'Travelmate' is a service, which employs people with a learning disability to support others to travel using public transport. This provides peer support and paid employment for people with a learning disability.

See: www.hailltd.org

Pooling Budgets (Ruils)

Pooling budgets allows those people with a learning disability to use all funds available, either personal or council, to share the cost of support, including holidays.

See: www.poolingbudgets.org

'I am Me' Scotland

The 'I am Me' was created to ensure that if someone feels they are being bullied, abused or harassed whilst they are out, they have "safe places" to go to. Window stickers are used in public places (shops, community centres and libraries etc.) that are part of the scheme to identify themselves as safe places. People can also carry contact 'I am Me' cards.

See: www.iammescotland.co.uk

2. Family and carers

The family and carers' love for their family member and determination to ensure the best for them was evident at every event. They spoke of their fear of losing the services and support they currently receive.

'The day centre is the only respite we have Monday to Friday and he loves this routine. As a family our lives revolve around my son. We don't have a life and can't have holidays or family events. We only just manage, but I don't know how much longer, as a family, we can cope.' Carer

It was apparent that at the forefront of their minds was a concern about losing support and services. This fear of losing what they value so much made imagining different possibilities difficult.

People talked about the need for their loved one to leave home and be settled with good support before they, as carers, are unable to care but few people had explored how to make this happen. Many people said that as resources are so limited, there would be no support to plan for the future.

'We want to plan for the future, but Social Worker told me there was no housing available and no funding. We haven't been given any information.'
Carer

We were told that the residential respite offered by Weavers Linn, as well as the respite provided by day services, that plays a key part in keeping the family together.

"My son loves to go to respite. Unfortunately, his visits are mid-week so as parents we don't benefit much from that, but I suppose most parents want a weekend." Carer

Many highly value the buildings, the staff, the range of activities and recent improvements. They talked about the pleasure of seeing their loved one looking forward to going to the service and their obvious enjoyment of the day when they return home.

"Our view remains that the day and respite services provided by Renfrewshire HSCP are first class, seek successfully to improve continuously on what they deliver, and should be maintained and funded sufficiently to support them in their excellent work." Carer

Some talked about their desire to explore different possibilities for their loved ones in terms of day opportunities.

Family and carers talked of the need to have information about the range of opportunities, including structured education and support available to enable to them plan with their child. For many, including those using personal budgets, this plan would need to ensure 5-day a week opportunities and support to ensure family and carers can continue to work.

"All the educational input and work that was given to my son as a child has resulted in a wonderful young man who has so much to offer his world. He shows me how I should live my life. Kindly, gently, determinedly and in connection with people. (I wish I could manage it!) Now the only offer he gets is one of four-day services."

Carer

Family and carers accept that the move to Self-directed Support is national policy and some families spoke about the positive benefits of Self-directed Support whilst many family and carers said their loved one has not been assessed for Self-directed Support.

When talking about Self-directed Support, people highlighted their struggle to:

- navigate a confusing process
- understand what is possible and
- find out what support and services are available

Importantly, family and carers want and need to know how much the existing services cost to attend, so that when they are informed of their personal budget, they can estimate what support the budget will cover. Families and carers also want support in finding Support Workers (Personal Assistants).

Family and carers accepted that support and services need to keep improving but vocalised that change for change's sake or in response to budget restrictions and policy drivers is a real concern.

"There is a need to keep moving forward – keep adapting – but no sudden change." Carer

Ideas for the future

Exploring different support and opportunities:

People would like to be able to 'pick & mix' from a range of services to create a varied and flexible week with a greater focus on community, education, volunteering and employment.

Information and advice

Family and carers would like a comprehensive and easily accessible information resource (online and in person) that gives a full range of options for people to explore.

Respite

Family and carers would like clarity about the number of nights respite allocated to individuals. They would also like additional respite options to be made available.

Planning for now and the future

Support with planning for the future is required, both in terms of when supporting someone to leave home and when their family carers can no longer offer support.

'As a parent we don't have much information where to go for help. I want to make plans for my son while I can, but I don't know where to start. It's really worrying.' Carer

Self-directed Support

Family and carers want to:

- know what budget they are entitled to
- know what services cost
- have information and support to understand what Self-directed Support is and how it works

Education, volunteering and employment opportunities

There was a clear desire for more opportunities for people to continue their education and secure volunteering and employment opportunities.

Gradual improvements

Family and carers requested that there be no sudden change and that any development should be gradual.

Work with us as partners

A resounding message from the family and carers was the request to be included, as valued partners, in shaping the development of services for their loved ones.

"As carers all we want is a good life for our loved ones. We try 24/7 to achieve that. Some acknowledgement that we are not the enemy and that we actually do a tough and unrecognised job might be a place to start."

Carer

Shared Lives

In 'Shared Lives', a young person or adult who needs support or a place to live moves in with or regularly visits (Respite) an approved Shared Lives carer. Together they share family and community life. It is extraordinary - because ordinary people open up their homes and lives to others all over the UK.

See: www.sharedlivesplus.org.uk/carers

Good practice examples from around the UK

Personal Assistant (PA) Pool

IBK Initiatives

IBK Initiatives work with individuals and families in Sheffield to help them recruit and manage Personal Assistants.

Their support is designed in response to requests from families. The service offers regular supervision for groups of PAs employed by families; networking and training events.

See: www.ibkinitiatives.com/support/PAs2GO

3. The day and respite staff team

Renfrewshire Health and Social Care Partnership staff spoke of their pride in the support and opportunities they currently offer. They explained how they have improved in recent years with new buildings and a wider range of opportunities. Whilst there was concern about the future, people expressed a strong desire to keep learning and developing new support and opportunities:

'We should go and see what people are doing in other places and bring some of the ideas here.'

Staff member

There were multiple conversations about how best to support people as they grow older and reach, what would typically be seen, as retirement age. Staff would also like to see different, more flexible support and opportunities for younger people.

There was a lot of discussion about how support should be more individually tailored. Staff ratios make this difficult, but the staff still have the desire for better.

Some staff spoke of the local pilot for the 'All About Me' plan, focusing on exploring what a good life would look like for the person. Staff are keen to know more as they believe this will lead to further improving the person-centred practice in the six monthly and annual reviews.

Staff explained that due to the numbers of people supported and the staffing ratios, the time people spend at the services is very structured. Whilst this may suit some, staff feel that many people would benefit from more flexible services, including support in the evenings and weekends. Importantly people spoke about the importance of people being able to spend more time with their friends out of the day and respite services. This would include evenings and weekends.

Teams talked about the lack of volunteering and employment opportunities.

Staff explained that the right space and structure for individuals is key to the success of the support at Gateway Intensive Support Services. They said there is little capacity to expand the service in the current site.

We were informed that staff turnover is low. However, we were told that 25% of the current workforce is aged 56+, and there was concern about potential staff changes in the coming years.

Staff said there had been cuts to the training budget. This concerns them, as often very specific skills' training is essential on a regular basis.

Staff celebrated the fact that in recent years, more and more connections have been made with community-based organisations to extend the choice to those supported. They talked of their desire to make more community links.

The majority of people currently supported live at home. Teams highlighted that they and carers are uncertain about the options and support available for people to leave home. Future planning is essential to avoid crisis.

The teams also spoke about the importance of respite for families. The staff are aware of the fact that the families would benefit from more respite.

Staff commented on the fact that current transport arrangements limit their ability to offer a more flexible service.

It was the energy, knowledge and passion of many staff in the workshops that lead to the sharing of ideas for the future as listed below.

Ideas for the future

Age appropriate support and services

Staff would like to see more age appropriate services developed, for example, for those reaching retirement age.

More flexible support and opportunities

The teams would like to see more flexible services that cover evenings and weekends.

Support to travel

Staff would like to explore initiatives such as 'Travel Buddies' and other travel training offers.

Involve us

Staff would like to meet some of the senior managers and Joint Integrated Board members to engage in the long-term planning of support and services. Their ideas, knowledge and experience are important.

Volunteering and Employment Support

Capacity and skills of the staff need to be developed, and connections made with partners to ensure more people are supported to aspire to, and secure, voluntary roles and employment.

Individually-tailored support

Staff are keen to develop more individually tailored support through pilots such as the 'All About Me' plan.

More community-based opportunities

Staff would like to see more inclusive, non-learning disability specific community opportunities opening up to people.

Access to Flexicare:

Rather than having to rely on a referral from a professional, the team would like to see people being able to enquire and request to participate in their chosen activity at Flexicare. This could be as a self-funder or via an allocated personal budget.

Closer work with Children's Services:

The team at Flexicare have identified the need for initiatives such as theirs to be available for children and would like to further develop links with Children's Services.

Self-directed Support

Staff are keen to have a deeper understanding of Self-directed Support. Some staff are also keen to explore the idea of people directly accessing more 1:1 and small group options via Self-directed Support or self-funding.

Support to recruit volunteers

Recruiting volunteers has become a lot harder in recent years and as the quality and capacity of Flexicare depends on volunteers, staff are keen to explore new ways of recruiting volunteers.

Community Networks in different localities

People talked about the need for Community Network projects in other localities that could offer similar support but stay small and locally connected.

Participation Officer

People talked of the need to further develop the role of the Participation Officer to ensure teams know the time and skill of the Officer is available to support all services.

Implement the interventions recommended in the national report 'Micro-Segmentation Report'¹⁸

The Autism Connections team are keen to implement the 8 interventions recommended in the report, which are designed to promote better outcomes and reduce unnecessary costs.

Future planning

Some staff would like training in relation to supporting families to plan for the future and to have information about where else families can get this support.

Meeting future demand at Gateway Intensive Support Services

Develop an offer supporting people with a complex learning disability and autism at home, this should be flexible and available in evening and weekends depending on the needs of the person.

Additional technology to enhance the work

Staff are keen to explore how additional assistive technology and general technology could help individuals.

Sharing best practice and training

To support learning, teams are keen to share best practice and learn with other services locally, regionally and nationally.

Creative respite

Staff are keen for respite to develop in a variety of creative ways that responds to local need. For example, respite in people's homes, small group holidays or for 'Shared Care' to be developed for adults as a 'Shared Lives'

¹⁸ <https://www.gov.scot/publications/microsegmentation-autism-spectrum/>

option.

Opportunities for older people

Teams would like to explore the possibilities of support and services for the elderly. Support that is suitable, close to home and meaningful. It doesn't have to be learning disability specific and could be intergenerational.

The Gr8 Support Movement (Paradigm)

The Movement is the first of its kind. It is value-based, thought provoking, encouraging and highly interactive. It deploys contemporary approaches to develop genuine connections and facilitate shared learning and mutual support across the UK. The Movement encourages direct Support Workers to connect, share and be the best they can be

See: www.paradigm-uk.org

Good practice examples from around the UK

Social Enterprises (Aldingbourne Trust)

The Aldingbourne Trust, in West Sussex, has developed a range of social enterprises to ensure individuals are enabled to develop skills and add value to their community, using social enterprise as the core model. The enterprises create opportunities for learning new skills and gaining experience as well as increasing the Trust's sustainability by providing top quality products and services for the local community.

See: www.aladinabournetrust.org

Self Build Social Care

'Self-build Social Care' is a collaborative research project. The project is finding out how adults with a learning disability and their supporters are seizing opportunities in the shift from day services to community lives. It is funded by the Economic and Social Research Council with a team from Dundee and Southampton Universities.

See: www.selfbuildsocialcare.wordpress.com

4. The community staff team

This team is a multi-disciplinary team (Social Workers and Health Workers) who work alongside those involved with the day and respite services. They have responsibility for assessing and reviewing people seeking support in terms of eligibility and on-going support.

The team talked about the progress that has been made in the last few years in terms of the range of support and opportunities available to people with a learning disability within the day and respite services.

Ideas for the future

Evening and weekend support and opportunities

Whilst the team appreciate the range of opportunities that are available between 10am and 3pm, they would like to see an increase the range of support in opportunities available in evenings and weekends to reduce the loneliness and isolation experienced by the people we support.

Annual Reviews

Clarification is needed over who 'calls' the annual review of the Care Plan: the day service team or the Community Team?

5-day a week support

Design and develop a 'mixed' week of opportunities but stress that a 5-day week support offer is essential so families can continue working or having some respite.

People being involved in hiring their own staff teams

As more people are assessed under Self-directed Support, some will choose to recruit their own staff teams. People and families will need support with this, for example, where to find and employ a Personal Assistant (Support Worker).

People with a learning disability having the opportunity to explore loving relationships

The Community Team members regularly hear about the wishes of people supported to find boyfriends/girlfriends and have their own families. In the future they would like to see people supported to explore love and relationships, for example, a course for people to explore love and

relationships.

Reduction in paperwork and regulations that limit flexibility

The team explained that in recent years, there seems to be an increase in paperwork and regulations and a growing concern that the ability to respond to individual wishes and needs are being limited. They would like to see a review of the paperwork, rules and regulations to ensure that only the necessary and constructive process and systems remain.

Positive approaches to risk taking

The Community Team should work with day service staff to explore how positive and creative approaches to risk taking are developed.

Dementia training for family and carers

People are living longer so there are more people developing dementia than in the past. There is a need to develop the skills and understanding of family and carers and staff to ensure people are supported well.

Better public transport

In some areas of Renfrewshire, public transport is limited, which may result in people being socially isolated and lonely. There is a need to work with the council and transport companies to improve public transport in some areas.

New Directions Ireland

New Directions is one of the key policy documents contained in the Transforming Lives Programme in Ireland. It sets out an approach to day services that envisages all the supports available in communities that will be mobilised so that people with disabilities have the widest choice and options about how to live their lives and how to spend their time.

See: [Easy-to-read-interim-standards-for-new-directions](#)

Good practice examples from around the UK

Pooling Budgets (Ruils)

Pooling budgets allows those people with a learning disability to use all funds available, either personal or council, to share the cost of support.

See: www.poolingbudgets.org

5. Independent provider colleagues

The representatives from eight provider organisations we met with were very positive that, as providers, they now meet with each other more regularly. These meetings are enabling them to learn from each other and identify their different strengths.

They are keen to work with Renfrewshire Health and Social Care Partnership colleagues and other providers to avoid unnecessary duplication and to expand the opportunities available to people with a learning disability.

Ideas for the future

People being better informed about what is available and possible

There is a need for a central hub of information (online and in person) for people with a learning disability, families, staff and providers to know what is possible and available.

People and families having a better understanding of the costs and services

As more and more people are assessed under Self-directed Support and are aware of their personal budgets, all day, community and respite services must state clearly how much it would cost for a person to purchase elements of the offer.

Fewer people being referred to day services

As a result of improved individually designed support and an increase in people accessing community and alternative day opportunities, there should be a decrease in the number of people referred to Core Day Services over the coming years.

Pooling support

There is an economy of scale that needs to be acknowledged, so they will be, wherever possible, working together to connect people with friends, people with common interests, to share support and pool funding.

Strengthen the relationship with Renfrewshire Health and Social Care Partnership and other partners

It is important to strengthen these relationships in order to share ideas, develop opportunities and maximise resources both in the Community and in services.

Facilitate community courses

Day services could be restructured so that anyone interested from the community can take part in particular course such as pottery and yoga.

Create a spirit and culture for what is possible

The providers stated boldly that they want to work as partners towards a future where there will be a spirit and culture of what is possible.

Changing Places

The Changing Places Consortium launched its campaign in 2006 on behalf of the over a quarter of a million people in the UK who cannot use standard accessible toilets.

The campaign works to increase the number of Changing Places across the UK to ensure people are able to access the community alongside other citizens.

See: www.changing-places.org

**Good practice
examples from
around the UK**

Online Booking for Courses (ECL)

Essex Cares (www.ecl.org) are working with Paradigm to facilitate Planning Together events for people accessing their day opportunities. The aim is to discover what each person would like ECL to offer and then design an offer in response. ECL is also developing a 'online' booking option for people to choose and book their courses and activities.

Contact information for this work has been shared with RHCSP

Key Findings

From the start of the review process we became aware of the anxieties and concern of some people with a learning disability, family and carers and staff that our review would lead to the closure of services and a reduction in support and services, given the current financial challenges that health and social care services are under nationally.

We worked hard to reassure people that this was not the intention, as did Renfrewshire Health and Social Care Partnership. However for some, the fear of losing the support they currently receive and rely on potentially limited their explorations of what may be possible.

We have met family and carers all over the country who have advocated on behalf of their loved one, often for decades, in a system which historically has not included family and carers in open, honest conversations about shaping plans for the future of the services. The resulting concerns and lack of trust are, we suggest, understandable and we believe one way to alleviate these concerns is for Renfrewshire Health and Social Care Partnership to commit to co-producing all future ideas and plans alongside a range family and carers with different wishes and views (plus other stakeholders).

Many parents, but not all, said that they were happy with the day and respite services and that no change was required. This was often repeated by the people we met who had a learning disability – that is until the conversations grew.

As the conversations grew, so did the ideas of people with a learning disability. They spoke of ordinary life desires for pets, relationships, voluntary roles and jobs, having their own homes and to see their friends in the evenings and weekends. Sadly many things that too often are not within the reach of people with a learning disability.

We believe it is important to reflect on the fact that 35% of those attending the day services have moved out of the family home and are living with support in their own homes. It is important to find out: Do they attend through choice or not knowing what else is possible? Or is there a lack of support and funding to enable them to have a more flexible, ordinary life?

"My brother is one year older than me. His life will be different BUT he wants and should have the support to have all the ordinary things of life." Sister

We are aware that throughout Paradigm's engagement, there were some people – family and carers, people with a learning disability and staff who were still expressing the desire for things to remain the same. For some people it might be that that is absolutely what they want and need. For others the fear of losing what they have, limits their imagination and aspirations for what is possible in the future.

'Respecting people's lack of interest in change does not exempt support workers and professionals from the responsibility to build relationships that respectfully encourage people to imagine better and actively seek it.'

As Renfrewshire moves forward, it is important to continue exploring how to support people to feel valued and trusted to ensure their future that is rooted in 'ordinary life' aspirations and human rights. Developing a culture of honest and open collaboration to explore possibilities is essential moving forward.

"Collaboration is like carbonation for fresh ideas. Working together bubbles up ideas you would not have come up with solo, which gets you further faster."

Caroline Ghosn

One consistent message we had from all people was the need for information that is shared widely and easily accessible. We believe that bringing in good practice from around the UK is hugely important in terms of helping people imagine a different way forward for Renfrewshire Health and Social Care Partnership. We believe this will open up thinking and inspire creative, more person-centred opportunities and support.

"A lack of knowledge creates fear. Seeking knowledge creates courage."

Candice Swanepoel

Information is key to enabling people to feel confident in making decisions. For example, there is confusions and misunderstanding in relation to Self-directed Support and lack of information about how to plan for the future (medium-term and long-term).

In order for Self-directed Support to help people explore different possibilities people must be given clear information on how much money they have,

what support and opportunities are available and how much they cost. Only with this information and support will people experience the benefits of Self-directed Support. It is essential that all staff have information on what is possible too.

As detailed earlier in the report, far more people with a learning disability access day services in Renfrewshire than in other areas across the country. This does not meet the aspirations of national policy. This higher attendance may be the result of the local history of people wanting building-based services and the subsequent investment in creating new buildings for the core services, rather than looking to create more community-based alternatives opportunities.

Respite is hugely important to people with a learning disability and their families but there needs to be a greater range of respite available both to increase choice and availability. This is absolutely key to enabling families to stay together and offer the support required.

In order to ensure be truly person-centred support and planning, Key Workers must have the capacity (time and skills) to discover with each person what a good life could look like for them.

We are keen to highlight that it is really important to focus on developing and valuing the skills of the staff who spend their days alongside the people who access the services. This pool of staff, across all the services brings passions, intrinsic skills, and interests that could be better harnessed.

In recent years, teams have become more outward looking - seeking opportunities to engage with local community opportunities. There is a need to further develop the skills required for this.

The outcomes of 'Keys to Life' are most evident in the work of: Community Networks, Gateway Intensive Support Services and Autism Connections and Flexicare, (established 29 years ago) which was, in many ways, ahead of its time. These services have a strong focus on support, prevention and skills development.

These are smaller services, with a clear focus on a specific group of people and they are under less pressure to meet the demands of a wide range of people in terms of ability and numbers. Individual outcomes are clearly

harder to achieve when you are in a service supporting 70 plus people with a vast range of needs and desires. Often the only option is to be part of a group, reducing the ability for people to have flexible, individualised support to live good, ordinary lives.

We want to recognise the strong drive in people to do what is right with and for people with a learning disability. This drive, along with the recommendations we have made below, needs to be harnessed in the creation of a Learning Disability Strategy – a strategy that is co-produced with a wide range of partners from its beginning (including the wider community of Renfrewshire, for example, housing, transport, employment); and has the voice of people with a learning disability at its core.

Recommendations

Paradigm's recommendations are based on the ideas of all those who engaged in the review, national good practice and policy, as well as our extensive experience of working across the UK.

Theme 1: Strategic Direction and Relationships

1. Co-produce a Learning Disability Strategy, which encourages people with a learning disability to live an active life as part of an inclusive Renfrewshire.
2. Continue to build positive relationships between family and carers and Renfrewshire Health and Social Care Partnership. Ensure current forums for family and carers have opportunities to share their diverse range of views.
3. Increase partnership working and commissioning of services delivered by the third sector and community partners.
4. Publish the cost of attending Health and Social Care Partnership services, to enable people to make better informed choices for their care and support.
5. Learn from other areas and support tests of change to translate creative ideas and potential into practical initiatives. This will enable new ways of

working to be tested on a small scale and expanded thereafter as determined by their success.

Theme 2: Day Opportunities

1. Continue to improve the existing day opportunities in Renfrewshire moving closer to a more flexible community-based model which increasingly works with the third sector and community partners.
2. Move towards a service model which includes evening and weekends where possible.
3. Work to improve access to a wide range of travel options for people with a learning disability, enabling greater choice and independence in their day-to-day lives.
4. Work with partners to further develop programmes to support people with a learning disability into sustainable paid and voluntary work.
5. Work with educational establishments to further develop the post school education opportunities available to people with a learning disability and the support systems required to enable success.

Theme 3: Respite & Short Breaks

1. Review the allocation policy and its application for residential respite at Weavers Linn, to ensure fairness and equity for all those accessing the service.
2. Explore alternative models of respite, for example, 'Shared Lives', whereby an approved carer opens their home to share family and community life to a person with a learning disability.
3. Explore ways in which the Health and Social Care Partnership may support people to consider wider alternatives to respite, for example, people going on holiday together or pooling budgets.

Theme 4: People and Process

1. Further invest in the development of support staff to continually improve

their skills, enabling them to deliver increased person-centred planning and practice across all services.

2. Support guardians to fully understand and carry out their role in line with the principles underpinning the Adults with Incapacity (Scotland) Act 2000.
3. Further improve the individual planning with people with a learning disability to explore the full range of opportunities, particularly at key transition stages:
 - a. moving into adulthood
 - b. leaving home
 - c. gaining employment
 - d. retirement
4. Develop information, advice and guidance resources for people with a learning disability, their families and carers to navigate options and opportunities available to them, for example, Self-directed Support.

Conclusion: What More is Possible?

International good practice shows¹⁹ that supporting people to live good ordinary lives is achieved when we focus on one person at a time and consider all the skills and resources available to the person in terms of community, family and money. All this must be used creatively to support the person to live a good ordinary life within the community and not solely in separate building-based services for specific groups of people.

The challenge to stay focused on the RIGHTS OF ALL to live good ordinary lives and to meet more than just the basic needs of a growing number of people with reduced financial resources, is an international one. But it is a challenge we must take on.

People need to know they have the right to expect more. People need information to make life decisions. People need to be inspired by good practice from nationally and internationally, that will help grow support and opportunities. People need to be valued and welcomed as equal partners.

¹⁹ O'Brien, J. (2017) What More Is Possible?

The people we met were proud of the services that already exist and this is a great starting place for Renfrewshire Health and Social Care Partnership to work from. Renfrewshire commissioned Paradigm to facilitate this review because they want to continue learning from and making plans with all those involved with the services.

There are many possibilities that lie ahead. Even in the short time that Paradigm worked with Renfrewshire, people began to ask more questions and grow their ideas, developing a curiosity for what else is possible.

The success of what happens next, is dependent on how all those involved in this review and the wider community of Renfrewshire, work honestly and openly to create the way forward. The question that needs to be asked as Renfrewshire moves forward is:

'What more is possible?'

(O'Brien, J)²⁰

²⁰ Ibid