

Agenda Item	7
Report No	HCW/20/23

The Highland Council

Committee: Health Social Care & Wellbeing Committee

Date: 25 November 2023

Report Title: Update on Disability Services in Highland including Self-Directed Support and Respite

Report By: Executive Chief Officer Health and Social Care & CSWO

1. Purpose/Executive Summary

This report seeks to offer an assessment of the Children's Disability services in Highland Council (HC), including commentary on Self-Directed Support and Respite. At the present time, there is a need to articulate the unprecedented challenges in delivering services to children with disabilities and their families. There is a complex picture of traditional in-house services, balanced against the approach set out in the self-directed support legislation which promotes choice and independence.

It is important to take into account that in addition to those children and their families who receive support from the Disability Service which sits within the Health and Social Care Service, there are many children and young people who do not receive such a service but are nevertheless affected by a disability. Those young people are likely to receive support from Education and may go onto receive an adult social care service. The Committee will be aware that this is provided by NHS Highland.

The transitions process from all children's services to adult services is key. It is important to consider all those groups when considering how service can best be delivered to offer the best possible outcomes to all stakeholders.

It may be that there will require, in due course, to be a formal review of disability services offered by the Highland Council. However, in the first instance the service is carrying out a scoping exercise which will consider existing provision and the context in which that provision is being delivered throughout the Highland area. That scoping exercise will include work with Education, NHS Highland and 3rd Sector colleagues as set out in the preceding paragraph.

2. Recommendations

2.1 Members are asked to:

- i. **NOTE** the contents of the report.
- ii. **APPROVE** the scoping exercise which is being carried out in the terms provided for in this report noting which requires engagement with NHS Highland in terms of Transitions and Education for those young people with a Disability who may *not* be known to the Children's Disability Service in Highland, as well as 3rd Sector partners.

3. Implications

- 3.1 **Resource** - There is no resource issue at this stage but there may be implications from any subsequent strategic review of Children's Disability Services.
- 3.2 **Legal** - Some of the key legislation that sets out statutory duties for children and families with disabilities are: s22 (duties to children in need) s23 (duty to assess) of the Children's (Scotland) Act 1995; the Social Care and (Self Directed Support) (Scotland) Act 2013; the Carers (Scotland) Act 2016 and the Children and Young People (Scotland) Act 2014 (duties in relation to integrated planning and delivery of service including a Child's Plan).
- 3.3 **Community (Equality, Poverty, Rural and Island)** - Children and families with disabilities face several significant disadvantages and challenges in society (e.g. prejudice, higher risk of inequality, poverty, poor health, etc). Some of the challenges can be compounded by barriers, including accessibility of services when living in more remote and rural areas. The Equalities Act 2010 should legally protect people from discrimination in society; children with disabilities have a right to equal treatment given *protected characteristics*. Family members/carers also have special provision in the Act given their *association* with the child with protected characteristics.
- 3.4 **Climate Change / Carbon Clever** – No implications
- 3.5 **Risk** - There are risks to children and families' health and wellbeing if they are unable to access the range of services required to support the child and the family's needs. 3.2 highlights the statutory duties to have in place a range and level of services to meet strategic needs, particularly noting the additional, and more intensive needs of children with disabilities. This report details the complex challenges in the delivery of services for children in Highland. There are considerable risks to the child and family - if they do not get the right help, at the right time, which may result in the breakdown of care. There is also the interlinked organisational risk of not being able to fulfil statutory duties noting workforce and service challenges.
- 3.6 **Health and Safety (risks arising from changes to plant, equipment, process, or people)** – No implications
- 3.7 **Gaelic** – No implications

4. Background

- 4.1 The Health and Social Care Service has two Children's Disability Teams based in South and the North. These are small specialist multi-disciplinary team(s) comprising of social workers, learning disability nurses, autism practitioners and social care workers, called community children's workers. In addition, there are individual social workers delivering a service in the more remote rural areas. This effectively is a hub and spoke model of service delivery in the Highlands. The team work collaboratively with children, young people, families, and other service providers, including, charities and third sector partners. Together they undertake a holistic assessment of need, with the provision of care and support based on this need.
- 4.2 In addition to the disability teams, the Council employs a small group of dedicated specialist services in Physiotherapy, Dietetics, Occupational Therapy, Speech and Language, and Primary Mental Health Workers (linked to CAMHS). These Allied Health Professionals supplement the services offered to children and families affected by disability. Key in terms of that work, is engagement with education in terms of presenting additional support needs in school and transitions to adult social care services once a young person reaches an age where he or she is leaving school.
- 4.3 The Children's Disability Teams work from the *social model* of disability, which describes people as being disabled by *barriers* in society, not by impairment or difference. The team focus on good conversations about the strengths of the child, the family and the community, seeking to build the networks of support.
- 4.4 The Committee will be aware that the national practice model **GIRFEC**, is the pathway of support to ensure the wellbeing of children, providing the right help, at the right time. For most children the family meets the child's developmental needs. Such support is provided by universal services and if early help is requested, this would be the responsibility of the Named Person in Health or Education. Children who require additional, and, intensive support, because of their disability, can be referred to the Children's Disability Team. A Lead Professional in health or social work is agreed with the family to coordinate the child's plan. Everyone working within the GIRFEC Practice Model, across the whole system (e.g., GPs, specialist health care, education and 3rd sector) have a role in providing high quality support to children and families affected by disability.

When a family is assessed as requiring support from the team, this can, for example, be in terms of respite or additional support. Traditionally that would be provided in house by staff within the Health and Social Care Service. However, it is particularly important in terms of service provision for families effected by Disability to consider the impact of the self-directed support legislation. Put short this provides options of support for families which might include direct service provision that is a traditional service provided by the Service (referred to as Option 3) or a direct payment which is payment made to the family such that they source and pay for support directly (Option1).

5. Self-Directed Support (SDS)

- 5.1 In terms of support provided by families, the role of Self-Directed Support is important. It extends across all social work and social care provision and also has a role for young people as they transition into adult care services.
- 5.2 The Social Care (Self Directed Support) (Scotland) Act 2013 (SDS) came into force in April 2016 to shift the culture of practice towards personalisation, co-production of outcome-focused provision, underpinned by human rights (SG, 2021). The importance of language and dialogue is emphasised with a focus on good conversations promoting choice, flexibility and control.

The four main **options** outlined by the legislation are as follows:-

- 1) Direct payments to where the recipient sources and manages their support.
- 2) A 3rd party, sometimes referred to as a community broker, to source and manage support.
- 3) Services directly provided from the Council or NHHSH.
- 4) A mixture of the other three options

In terms of direct payments (option 1), many families can choose to employ personal assistants to provide support. A personal assistant (PA) may come into the family home and remain overnight, allowing parent(s) to go away for a short break. Families are choosing this more personalised approach rather than traditional respite care out with the family home and that is the intention of the legislation. It should however be noted that in the current circumstances where in house (option 3) solutions may be limited, that there are cases where an Option 1 Direct Payment is the only means of obtaining support. The Service is mindful of this.

6. Respite Provision in Highland

- 6.1 Traditionally services have been provided directly by the Council. As such if a family is assessed as requiring support or respite care, that care would have been provided by Council staff using Council resource and premises. In terms of the SDS legislation it is now open to families to make their own arrangements. However, the Council does continue to provide direct service and that provision is considered within these paragraphs.
- 6.2 **The Orchard** has been operating as an integrated **residential** and **respite care** (short break) service since 1995 in Inverness. It provides short break stays for children and young people affected by complex health and disabilities. The service provides 24-hour care with waking night staff. The staff are a multi-disciplinary specialist team of qualified nurses, and social care staff.

The Orchard comprises of:

<p>Badgers (3 bed) – residential care. No 54 (2 bed) linked house – residential care. Applegrove (2 bed) linked house – residential care.</p> <p>Foxes (4-bed) – up to 4 children – short breaks.</p>

Squirrels (4-bed) – up to 4 children – short breaks.

- 6.3 No 54 (2016) was commissioned to bring young people back to Highland who had been placed out of area to be closer to family. Applegrove (2021) was commissioned to stop young people having to be placed out with the Highland area to remain close to family.
- 6.4 The residential provision houses 7 children who are 'looked after' away from home. Such children reside there on a more long-term basis. Children who require residential care have highly complex needs, including neurodevelopmental spectrum disorders (e.g., autism and ADHD). A small minority of children may also have been exposed to additional harm.
- 6.5 The Orchard also has the capacity for 8 children and young people staying for short breaks or respite. The Orchard and other respite provision supports families to have time away from the challenges of caring and supports the health and wellbeing of the whole family. Many families tell us that the Orchard is a 'lifeline' that is supporting families to stay together.

The Orchard is facing considerable challenges at the current time. The residential provision is full and therefore any children with complex disability needs, who are at risk, cannot be accommodated. Due to this 'blockage', the short break (respite) service has been suspended since July and crucially, has not been available over the summer holidays and the October break - when families most need a short break service. Council staff and colleagues in NHSH are working hard to get the respite provision back in place.

There have been several cumulative factors that have resulted in this current situation. Essentially, there has been a '*perfect storm*' of systemic factors - that has brought the service to this point. It is important these are understood as the situation is not simple nor is it about individual failings.

The main issue stems from the inability to transition some young adults who had residential placements into their own homes with a personalised community care package. Each care plan is highly complex, requiring adapted accommodation, and skilled care teams, to ensure the safety and support of the young adults. Adult Services in NHSH are facing major challenges in the recruitment and retention of a range of health and social care roles to enable young people to move into care in the community.

The impact of this on families and young adults who are in transition cannot be understated. However, it is also important to acknowledge the broader impact on all those families who need a short break.

- 6.6 In addition to the Orchard, there had also been in-house respite provision in Caithness. During the pandemic Thor House, which was a smaller provision for short break, respite care, in Thurso, was needed to respond to children at risk in the community. Consequently, the house stopped being used as a short break service. In contrast to The Orchard in Inverness, this had less of an impact in the North given the smaller numbers and population size with more families moving away from traditional building-based respite linked to choices through self-directed support.

There are currently no other respite in-house resources available in Highlands. The Service recognises that the discontinuance of services – whether it be permanently as in Skye, or temporarily suspended within Inverness, has had a significant impact on families affected by disability. Staff are working hard to consider alternative means of support which includes other SDS options.

The Service does offer respite provision using the **Fostering Short Break Service**. Highland Fostering Service has five carers who provide regular short breaks to six young people affected by disability. As there is a waiting list and a shortage across Highland of foster carers providing short breaks for children with disabilities, focused recruitment drives will continue taking a more targeted approach required for this specialist fostering. The Fostering Service is key in terms of the Shared Lives implementation which is ongoing with NHS Highland in terms of supporting people locally and ensuring that where an option 3 direct service is required that this can be provided.

Notwithstanding the current challenges in terms of in-house respite provision there are a range of activities for children and young people aged 5-19 across the Highlands. These include after school clubs, holiday schemes, weekend activities and youth clubs. Highland Council also commissions, The Highland Community Care Forum - Connecting Carers and various young carers organisations such as Skye and Lochalsh Young Carers Service and TYKEs, a young carers service in Sutherland. These organisations provide a crucial service to families affected by disability and to siblings of children who are disabled.

7. Transitions in Highland

7.1 **Transitions to adult services** are a key and challenging area and have been discussed at Partnership level for some time. In terms of that discussion a pathway has been agreed with NHS Highland which sets out timescales of future planning for children and young people who will be eligible for adult care services. Some of that work involves children who are known to the Disability Team, but many are not and transition direct from Education where they present with complex health and disability needs but are being looked after at home without any SW services.

7.2 There are two approaches to managing transitions for young people to Adult Services through one dedicated transition team. That team is multi-disciplinary consisting of adult social workers (NHS), and children's social workers (HC). Staff are co located and work together to provide a transitions service. The team is referred to as the Transition Team and its geographical remit is limited to the Inner Moray Firth.

Out with that, transitions elsewhere in Highland are managed by the specialist disability workers in Children's Services who link in with District Teams within NHS Highland. Local practitioners from NHS Highland and HC work together and follow the same transition pathway, finding solutions and pathways for young adults with a disability.

It is recognised that transitions are key for this cohort of young people, with the Joint Monitoring Committee triggering and monitoring a programme of work to consider this area of service provision. Challenges relate not only to ongoing service delivery, but also the resource implications in relation to significant care packages particularly once educational provision ends. That work is ongoing and extends to the preparation of a transition's pathway referred to above.

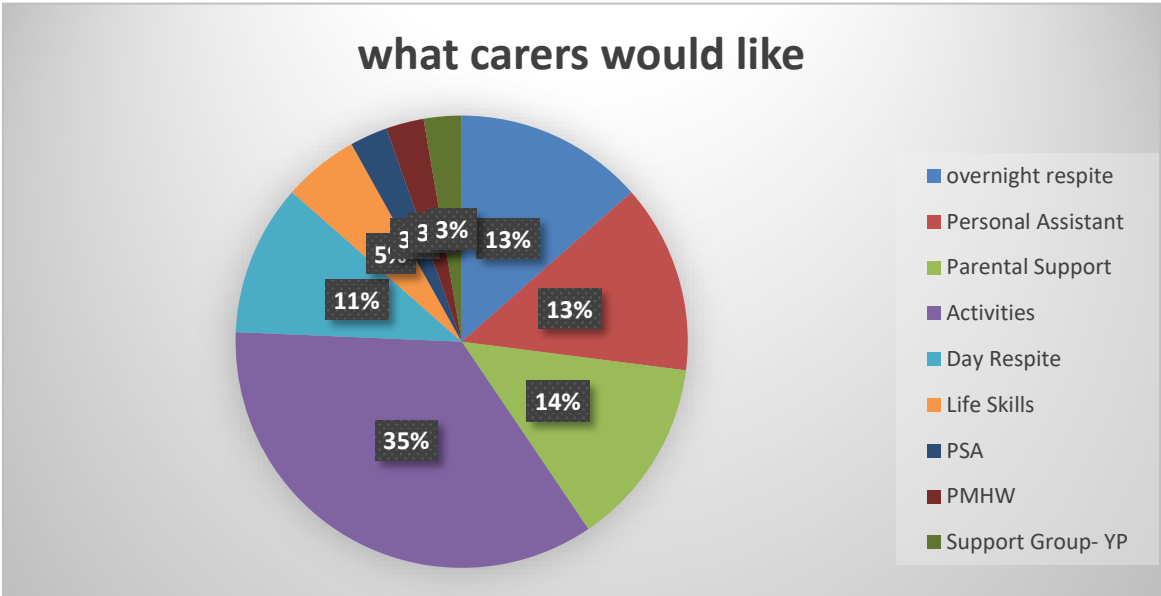
There is further work ongoing in relation to housing solutions and joint commissioning which are outside the scope of this report. It is a key part of that transitions work to implement the Shared Lives schemes such that, for example, foster carers who support children effected by a disability whether by way of offering respite or more permanent living arrangements, can be approved as adult providers once young people move on from Children’s Services.

8. Next Steps and the Scoping Exercise Required

8.1 Understanding need in collaboration and engagement with children and their families is important in planning services. The Joint Strategic Needs Assessment (2023), commissioned as part of the integrated children’s services planning process, highlights an increasing number of children with additional support needs, including learning, speech and language, social and behavioural, communication and problem-solving. It is key that there is engagement with education in terms of transitions in particular so that all children and young people who are affected by a disability - and are likely to be eligible for an adult care service - are identified at an early stage.

It is essential we listen to the voices of parents and young people as we move forward with the improvement and planning of services based on what families tell us is important to them. That work has commenced in Caithness and Sutherland where we have been working with our 3rd sector partners along with parent representation to map current provision. Developments from this collaboration included initiating a targeted recruitment campaign for short break foster carers and an Easter Activity Day.

8.2 Below is a table of responses from parents detailing what they would like to see for their child. Notably, building more supportive fun and recreational activities was a priority for **35%** of parents.



Highland Council and NHS Highland are already working together in terms of delivering transitions to strengthen SDS across Children’s and Adults through an appreciative enquiry process which is asset-based and builds on existing strengths and opportunities within communities. The areas of focus include:

- Early planning for transitions
- Flexible and outcomes-focused commissioning
- Risk enablement
- Worker autonomy

8.3 The provision of respite for families and children effected by a disability is challenging. Whilst there have been some new independent services which have opened recently, the scoping exercise being carried out will consider all services available across Highland and how they can provide necessary services to young people, families, carers and adults with disabilities through the provision of the various SDS options.

There is of course much more to do to support children and families across the Highlands who are living with disabilities. The situation within The Orchard must be resolved as it is accepted that short breaks maintain the health and wellbeing of the **whole** family. In doing so this prevents families from moving into crises with the risk of the breakdown of care.

8.4 This report acknowledges the scoping exercise currently being carried out in relation to the services available for children with disability in Highland. The aim of this exercise is to understand and assess the resilience of the system to meet the needs of children and families with disabilities in Highland. In order to fulfil our statutory responsibilities across a range of family supports - from preventative health and social care services to more targeted and intensive support for the 'critical few' who require this specialist provision in Highland – we need to fully understand what need and support is required, to then enable the correct resources to be in place.

On completion of this scoping exercise, we will be more informed as to what next steps are required to ensure that there is strategic overview, planning and collaboration across the sector with children, families and carers within disability services.

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