

Social Work Services for Children with Disabilities

Education, Children and Families Committee

9 October 2012

1 Purpose of report

- 1.1 The purpose of this report is to update the committee on the progress made in the service area of disability.

2 Summary

- 2.1 The legislative base for the provision of services for children and families affected by disability is changing. Local Authorities have duties and powers under the Children (Scotland) Act 1995 to:

- Minimise the effect on a disabled child within the authority's area.
- Give these children the opportunity to lead lives as normal as possible.
- Carry out an assessment of the child and family and a 24) assessment of the needs of carers.

The Social Care (Self-directed Support) Bill is likely to come into effect by March 2013. This will place a duty on the Local Authority to explain the nature and effect of four options for service provision:

- Direct Payment
- Individual Service Fund
- Local Authority delivery of services, or
- a mix of any of these options.

The Bill's remit is likely to encompass:

- Children "in need" as well as disabled children.
- 16 and 17 year olds being able to direct their care.
- Views of children being taken into account.

- A discretionary power to provide support following a carer's assessment for carers and young carers.

This will have implications not only for disability services but for children in need, and carers. A task group is being set up to address these issues working jointly with our Health and Social Care colleagues and partner agencies.

- 2.2 In addition the Children and Young People's Bill 2013 will provide further legislative support to our work by focusing on improving outcomes through earlier support and joined up services. In 2008 the City of Edinburgh Council established a dedicated social work team for children and families affected by disability. The team includes occupational therapists and social care workers. Demand for services will continue to rise as a result of demographic pressures. The Scottish Households Survey (2009) suggests 5% of 0 – 15 year olds have a disability and/or long term illness that limit their daily activity. The predicted mid year estimates for 2011 suggest there are 78,074 0 – 16 year olds in Edinburgh. This suggests there are up to 3,900 0 – 16 year olds in Edinburgh with a disability and/or long term illness that limits their daily activity.

The number of children and young people in Scotland is predicted to decrease over the next 10 years. The number of children with severe and complex disabilities is increasing. Many children with profound and multiple disabilities are now surviving through childhood to adulthood due to advances in medical intervention.

- 2.3 Children affected by disability are 3 to 4 times more likely to be abused than non-disabled children (NSPCC 2011). Research has shown that children with communication impairments, behavioural disorders, learning disabilities and sensory impairments are particularly vulnerable (Sullivan and Knutson 2000).
- 2.4 We are aware of a growing number of children born to families with substance abuse issues. Some of these children are affected by disability due to the impact of substance abuse during the gestational period. A rate of 16.1 per 1000 maternities were affected by substance abuse in 2009/10 compared to 9.4 per 1000 in 2005/06. This increase is thought to be due to better recording rather than an overall increase (IDS Scotland, February 2012).

3 Main report

- 3.1 The Disability Practice Team works to the same criteria and thresholds as Neighbourhood Practice Teams to ensure a consistency across the City. The team provides a service to:

- Children with a disability who are looked after or on a statutory order.
- Children who are looked after and accommodated.
- Children who are involved in Child Protection processes.
- Children who are involved with the Children's Hearing system.
- Young people who need assistance with the transition to adult services.

- Children who need support due to the impact of their disability.
- 3.2 The Disability Practice Team currently holds 540 cases. This is 128 more than last year. This may mirror the rising numbers of children with a disability requiring support, the current financial climate and the isolation many families experience when they have a child with a disability. The Disability Practice Team carries out the majority of Section 23 assessments. There are 17 families currently waiting for this assessment in contrast to last year's figure of 23. This assessment is the gateway to targeted support services. Section 23 assessments are prioritised using a rating tool (Appendix 1). This ensures an equitable and transparent process across Edinburgh and informs the level of service a family may be offered against our Edinburgh Threshold document (Appendix 2).
 - 3.3 Families can be considered for day services, youth groups or residential short breaks. Families are also offered a direct payment which enables them to arrange their own service according to their need. There are three short break residential units within Edinburgh, Seaview our in-house resource, Barnardo's Caern and Action for Children (financed 50% by Health). Families can also request for their residential respite to be delivered from Family Based Care if they prefer a family setting.
 - 3.4 The residential units all provide a valuable short break to families. The standard of care offered to the children is high and can be evidenced in their Care Inspectorate rating. The scores range from 4 (good) to 6 (excellent).
 - 3.5 There was a significant waiting list for short break residential services last year. The waiting list was for 71 children. This has reduced to 31. We have worked with the residential services to offer different levels of overnights dependant on need and we also offer an alternative to residential respite via an all day fortnightly club.
 - 3.6 We commission a specialised service from Action for Children with Health for children with severe and challenging behaviour. The children/young people who attend this unit have complex behaviours which can be unpredictable and can involve high levels of self injury or aggression. The families who use this service can access up to 70 nights a year. Most families would want more nights. The pressure of providing care alongside siblings and family life can lead to family breakdown. This can be a particular problem over the summer holiday period. This is an area that would be worthwhile investing a higher level of support in to avoid more substantial difficulties and we are exploring options to achieve this.
 - 3.7 The Occupational Therapy Team provides a community based service to families that require aids and adaptations within their homes for their child/young person's needs. They also offer a paediatric occupational therapy service to children who attend our Child and Family Centres. There is a waiting list although all crisis cases are seen quickly. We plan to work alongside our colleagues in NHS Lothian and Health and Social Care to improve our current service delivery.

Waiting List	Urgent Cases	High Cases	C&F Centre Waiting
February 2011	0	27	2
July 2012	0	47	3

3.8 Family Focus is a team that works intensively with families either at the point of diagnosis or when the children have high care needs. Family Focus will also work with children who have challenging behaviour in the community and at home. The team offers a service to 64 families and they have a waiting list of 14. The team has also recently run a group for families who have children with an early diagnosis of autism. This was well received by families and will be offered in the future.

3.9 We run various services which require a shortened assessment. There are three weekend services for children affected by disability. Two of the groups (Kidzown) run at the weekend covering the City. This offers families a day a month short break from 10.00am until 4.00pm. This service caters for children from the age of 3 – 10 years. Kidzown offers a service to 63 children. We have a club for older children (Youthzone 0 – 16 years) which caters for 20 children a month. Families can also access First Hand a voluntary agency we commission to offer a sitter service to children affected by disability.

4 Developments

4.1 One of our short break residential units Seaview is currently being rebuilt in the Bingham area of the city. The unit will be operational by June 2013. The development has been a dynamic process involving a high level of consultation with the community, Seaview staff and, most importantly, the children and their families. The new unit will increase capacity, provide services in a first class environment. The unit will also have a small suite of rooms which will be able to be used for the emergency care of children who are affected by disability.

4.2 Many families in Edinburgh have difficulty coping with children who have challenging behaviour alongside other family pressures. Children with a learning disability and/or Autism Spectrum Disorder often need a more specialised response to managing their behaviour compared to other children. We commissioned Barnardo's to provide an early intervention service (Barnardo's Intensive Behaviour Service) to families who come to our attention as requiring a period of intensive behavioural support in the home. This work involves staff from the disability area and has a high level of consultation from the Child and Adolescent Mental Health Team (learning disability). This work is being evaluated and refined by using an assessment process (the Sheffield Questionnaire) which was identified by the Psychology Service. Family feedback to date has been very positive.

4.3 The Barnardo's Intensive Behaviour Support Service (BIBBS) recently received funding from the Scottish Government from their Autism Strategy funding for an additional member of staff. This staff member enables the service to work with

children/young people with High Functioning Autism with challenging behaviour. This was previously an area of unmet need. The demand for this service is high so we have applied to the Early Years Change Fund to increase the capacity and to also try to respond to families in crisis where family breakdown is a possibility.

- 4.4 A small number of children have to be accommodated out with Edinburgh in residential schools when the demands of their care needs have resulted in family breakdown. Hillview Children's Unit was opened in April 2012. Hillview is a five bedded unit offering intensive support and respite to children/young people with disabilities. This new service has enabled us to prevent some children/young people going out of authority when care breaks down. We have worked with families and other support agencies to build on their capacity and resilience to enable their child to return home. We have supported 11 families since we opened and have three families on the waiting list who need involvement in developing sleep programmes for their children as they are exhausted and feel close to giving up the care of their child.
- 4.5 There are around 500 children and young people who use our playscheme service each year. Children with disability can access up to 3 weeks per year. Children attending Oaklands receive up to 12 weeks due to a historical agreement from when Oaklands was a 52 week School. Many families (particularly those from St Crispin's) struggle when their child no longer has the structure of School. We would like to increase the playscheme provision up to 6 weeks for all families with a child with a significant disability. This would require future financial investment.
- 4.6 The commissioning approach for Children's Disability Services is currently out for consultation to parents/carers children and young people and siblings. It is then intended a period of consultation will take place for service providers, colleagues and all other interested parties. All responses will be collated and will inform our commissioning approach for services currently and in the future.
- 4.7 We have set up a new Parents Forum which meets quarterly. This group is made up of parent/carers who use our disability services. The group considers service gaps, developments and any dilemmas that merit a parent's view on future service delivery.

5 Equalities Impact

- 5.1 Has been undertaken and no negative impact or infringements have been noted.

6 Environmental Impact

- 6.1 None

7 Conclusions

- 7.1 We continue to be aware of the growing demand for services from families with children affected by disability in Edinburgh. We are planning alongside our

partner agencies and families to address additional demands for services and work on identified areas together.

8 Recommendations

8.1 It is recommended that the Committee notes the content of this report.

Gillian Tee
Director of Children and Families

Appendices	1 Priority Rating Tool 2 Service Delivery Model
Contact/tel/Email	Carol.chalmers@edinburgh.gov.uk
Wards affected	All
Single Outcome Agreement	National Outcome 4 – Our young people are successful learners, confident individuals, effective contributors and responsible citizens. National Outcome 5 – Our children have the best start in life and are ready to succeed. National Outcome 6 – We live longer, healthier lives. National Outcome 8 – We have improved the life chances for children, young people and families at risk. National Outcome 15 – Our public services are high quality, continually improving, efficient and responsive to local people’s needs.
Background papers	Hyperlink to Disability Services Structure: https://orb.edinburgh.gov.uk/downloads/file/2841/disability_support_to_children_and_young_people

Disability Services - Priority Rating Chart

The Family (Applies to parent or main carer and their capacity to care for child/young person)

Concept	Level 1 None	Level 2 Some	Level 3 A lot of support	Level 4 Major/significant support	Level 5 Crisis/exceptional
Physical well being	Good physical health.	Some health concerns/physical condition	Ongoing unstable/significant: medical condition affecting capacity to care: <ul style="list-style-type: none"> Physical disability carer pregnant (6mths pre or post) awaiting minor in-patient care 	High dependency on medical intervention. Major in-patient care or recent or post -op care	Unstable health care requiring regular or emergency treatment & affecting caring role: <ul style="list-style-type: none"> palliative care chronic condition deteriorating condition
Emotional well being	Usually emotionally well.	Some emotional issues impacting on their well being.	Significant emotional issues impacting on their well being. Stable mental health maintained by medication.	Severe emotional issues impacting on their well being. Unstable mental health.	Crisis intervention, Hospital admission.
Family Support & responsibilities	Supportive & stable family network.	Family coping mechanisms reduced having difficulty managing. Unable to provide age appropriate time for siblings.	Insufficient supports available to meet whole family's needs. Recent changes in family circumstances, affecting coping skills.	Parental capacity to cope deteriorated, impacting on family's welfare Child/family victimised in their community.	Other caring roles including other sibling with a disability or dependents. Recent/on-going Child Protection concerns. Imminent risk of family breakdown. LAAC child with foster carers/ requiring additional support due to risk of placement breakdown.
Housing/ Economic well being	Housing and benefits/financial supports in place.	Minor adaptations or advice: <ul style="list-style-type: none"> grab rail benefits advice 	Adverse housing conditions impacting on welfare of child, i.e. dampness, no heating, no safe play area. Major adaptations required - ramped access/bathing. Adverse changes in financial circumstances.	Housing cannot be adapted to meet child's needs or overcrowded, requiring re-housing.	Crisis or specialist support/ Significant Housing Issues. <ul style="list-style-type: none"> unsuitable temporary accommodation impacting on child's welfare. child's hospital discharge delayed due to housing issues.
Coping Skills	Parent/carers coping well. Participates in family and community activities	Inclusion in family/community activities - requires advanced planning.	Unable to go out as a family since parents have to divide their time either with disabled child/sibling. Activities available but too stressful for family to attend. Family not engaging with services. Resistant to using supports. Parent with: learning disability substance misuser.	Family can only go out with significant planning and additional support.	Social isolation for family as no additional support available after school/weekends.

Revised June 2012

Disability Services - Priority Scoring Chart

The Child

Concept	Level 1 None	Level 2 Some	Level 3 A lot of support	Level 4 Major/significant support	Level 5 Crisis/exceptional
Physical wellbeing	No health or well being issues.	Requires regular review from health professionals. Regular medication. e.g. asthma, constipation, stable well controlled epilepsy Frequent or recurrent illness/infection.	Chronic condition usually stable but requires additional medical/health intervention, e.g. PEG feeding e.g. Requires regular emergency medication Moderate sensory impairment.	Unstable condition with frequent re-evaluation needed. High level of medical intervention. e.g. degenerative condition e.g. unstable epilepsy e.g. oxygen therapy Profound sensory impairment.	Terminal phase or life limiting condition. High dependency on medical intervention. Waking or overnight trained carer. e.g. ventilation/suction
Emotional Well being	Usually emotionally well.	Some emotional issues impacting on their well being.	Significant emotional issues impacting on their well being. Stable mental health maintained by medication.	Severe emotional issues impacting on their well being. Unstable mental health.	Crisis intervention due to risk of harm to self or others.
Access to social & leisure activities	Family and social support in place.	Access to social and leisure opportunities may be limited.	Support required to access social and leisure opportunities. This may only be required for a limited period of time.	Ongoing one to one support required to access social and leisure opportunities.	Ongoing trained carer support required to access social and leisure opportunities.
Physical Mobility	Independently mobile. Appropriate for age and stage of development.	Mobile can be unsteady/clumsy. Requires some assistance/aids.	Impaired mobility, direct prompting required, may use physical aids or supporting person.	Fully dependent, requires 1:1 support for transfers.	Fully dependent requiring transfers/hoisting.
Self-care	Appropriate for age and stage of development.	Care needs can be met with significant prompting, supervision: Dressing/undressing Eating/drinking Bathing/showering Supervision and verbal prompts with self-care	Fully dependent due to: challenging behaviour physical care needs but cooperative with 1:1 support. 1 person transfer with hoist	Fully dependent due to: challenging behaviour physical care needs but cooperative with 2:1 support catheterisation 2 person transfer	Fully Dependent and uncooperative requiring 2:1 support Catheterisation
Behaviour & Sleep	Age and Stage appropriate, no difficulties.	Behaviour can be managed most of the time. Sleep can be managed most of the time.	Challenging behaviour - can display aggressive/inappropriate behaviour. Sleep - needs attention some nights, one or two per week. Will settle again.	Highly challenging behaviour . Sleep disturbance which requires intervention most nights.	Unpredictable, frequent and intense behaviour , which is challenging. Sleep disturbance which requires intervention every night.

Getting it right
for every child in Edinburgh

Children with Disabilities Service Delivery Model

In partnership with voluntary & health services

CRISIS INTERVENTION

LOOKED AFTER & ACCOMODATED CARE

Family breakdown to reduce risk of child being cared for out with family and/or authority.
Crisis care determined by assessed needs, which may be time limited.

LOTHIAN EXCEPTIONAL NEEDS SERVICE (Lens)

Children with complex health care.
Packages may be funded from health, social work and education.

OVERNIGHT SHORT BREAKS/RESPITE

Residential or Family Based Carers

Dependent on assessed need & score.

Exception is Gilmerton Rd., jointly funded with health for children with severely challenging behaviours.

PANEL 3

Standardised Assessment carried out within principles of S23 Children's Scotland Act 1995

Score

27+

DAY SHORT BREAKS/RESPITE

Outreach/Spot Purchase/Direct Payment

2 – 3 hrs week for under 8 years

3 – 4 hours week for 8yrs – school leavers

Additional hours dependent on complexity/personal care

*Direct Payments scored and discussed out with panel

PANEL 2

Standardised Assessment carried out within principles of S23 Children's Scotland Act 1995

25+

YOUTH CLUBS SITTER SERVICE

Support ranges from a two hours per week to six hours a month.

PANEL 1

Social work assessment carried out within principles of S23 Children's Scotland Act 1995

23+

EARLY INTERVENTION SERVICES

Time limited support working in partnership with families.

Initial social work assessment carried out within principles of S23 Children's Scotland Act 1995

UNIVERSAL/COMMUNITY SERVICES

Partner Providers clubs and local community resources.

No social work assessment required

Children may access our services at any level dependent on their assessed needs. Their needs may increase or decrease, through review and monitoring, impacting on their priority and level of service. Services will take account of the child's priority score, whilst matching the child's needs to the service vacancy.