

Service Review

Short Breaks and Targeted and Specialist Provider Services for children with Severe and Complex Disabilities

1. Introduction and Context

This review was commissioned by Children's Services in December 2013. The review has focused on the statutory social care services provided to children with severe and complex disabilities as well as the resources that are provided to those children and examined whether they are offering value for money. This report summarises the findings and the work undertaken and what we intend to do going forward.

We will be carrying out stakeholder consultations during July, August and September 2015. If you have any questions or comments about this report or the planned consultation processes, please write to Nikki Ralph via email: nikki.ralph@islington.gov.uk. The consultation period will close on **18/09/2015**.

All consultation feedback received in relation to this report will be presented to Islington Council's Executive Committee in November 2015 for a final decision in respect of the proposals relating to Lough Road and the associated re-organisation proposals that are subject to formal HR procedures.

2. Key Findings and Actions

2.1 Assessing, planning and reviewing the needs of children with severe and complex needs

What we looked at

We looked at the current documents used to support the assessment, planning and review processes. We talked to managers and some of the staff in the Disabled Children's Team and the Early Support and Personalisation Team, who are involved in these processes and use the current tools and we looked at the quality and the timeliness of these processes for families.

What we found

We found that there were too many documents being used that seemed to duplicate each other and some of the documents are not legally required and are resulting in too much delay to

securing services for families. It also meant that social workers were spending far too much time assessing when they could be spending more time out in the community working with the families they support and ensuring that the services we provide are making a difference.

For example the social care assessment had a lot of information in it that then also featured in the Support Plan. The conflicting designs of these two documents meant that social workers were spending too much time moving information from one format to another. The Supported Assessment Questionnaire also required information to enable us to work out levels of financial support a family may need but again this was asking for existing information to be recaptured in a different format. One of the reasons this had happened was that the social care assessment were not recording enough information about the impact of the child's disability on family members and Child in Need plans were not being used to accurately capture the links between needs, outcomes and levels of services required.

We found that once support services had been put in place we were not reviewing robustly enough whether or not those services were actually making a difference to the child and his or her family and that many support packages had not been reviewed for over a year. We found that where reviews of support plans were taking place and changes were being proposed or had been made this was not always based on an updated assessment of need by a qualified social work practitioner where arguably there had been a significant change in circumstances resulting in the need for a change in the support plan.

What we have done so far

We discussed our findings with the social work managers and committed ourselves to rationalising the amount of paperwork to ensure that we reduced the time social workers spend doing assessments, increased the time they have available to spend with the families they need to support directly and to improve the timeliness of reviews to make sure that what we provide is making a positive impact.

We have phased out the use of the Support Plan and now capture information from the Supported Assessment Questionnaire as part of the Child and Family Assessment itself and only use the Child In Need plan as the basis for agreeing with families what the outcomes need to be for which service provision is required which may then require funding under section 17 (e.g. by way of personalised budgets). The redesign work for this has been completed and the new process is now in place. Targets for the timeliness of assessments and the production of plans and associated social care budgets have been agreed.

The approval and reviews of plans that include elements of financial support to meet social care needs are now presented at the newly established Education, Health and Care Needs Panel (this commenced in January 2015). At this panel Health, Education and Social Care senior commissioning representatives are responsible for ensuring that services we provide are making a real difference to families and that they represent value for money. They will also monitor to ensure that families are getting access to services they may also be entitled to in other universal

services where additional funding may already be provided to meet some of their needs (e.g. in schools).

What we are going to do next

We will be ensuring that reviews happen regularly, for most families this will be once or twice a year, the plan itself should determine how often reviews should take place as it will depend on things like how complex the plan is and how many services are involved in supporting the family and the nature of them. We want to rationalise the number of plans where possible and explore options for social care services to children in need to be written directly on to the Education Health and Care Plan and not have to subject families to multiple reviews about different plans. We have already started to have discussions with our special schools to agree a possible process for this.

If children are subject of a child protection plan or a care plan (for looked after children), reviews will be in line with those plans.

It is clear that in order to deliver the required level of CIN reviews per year or EHCP reviews where CIN services are incorporated, we need to ensure all reviews whether led by social care directly or via an EHCP review at a school have ultimate oversight and sign off by a suitably qualified and experienced social work manager.

To that effect we have proposed some structural changes to what is currently the Early Support and Personalisation Team by creating a 'Disabled Children's Family Support Team', with clearer separation of duties between case management and procurement/brokerage. The personalisation function will operate as a separate team supporting both DCT and the Disabled Children's Family Support Team where support plans need services set up or where families require provision by way of a personal budget.

The Disabled Children's Family Support Team will also link to or directly manage a new service function which is referred to later in this report. In summary this will be a time-limited and intensive home based parenting support service to help parents to manage the challenging behaviour of some children and young people who display severe challenging behaviours. This service needs to be specified and consideration given as to whether this should then be provided in-house or secured via an open tendering process.

Some of the children in this new service will be case managed by a social worker in DCT where there are concerns in relation to parenting capacity and/or safeguarding and the management of risk in the home. Therefore this service has to have robust social work management oversight and workers will be asked to contribute towards our statutory Child and Family assessments where an assessment is in progress.

2.2 Provision of financial support to children with severe and complex needs

What we looked at

We looked at the way in which we assess the needs of children and the support they need at home and the support their parents may need and how we then work out what kind of financial support they should be provided with.

What we found

We found that many children and families were receiving really comprehensive packages of financial support, either through direct payments or personalised budgets. We have a resource allocation system that helps us to work out an indicative budget which families can use to develop their support plan. However we have decided that this system needs to be reviewed in order to ensure the following potential problems or risks we identified are minimised.

- There needed to be closer alignment between the way Children and Adult's Social Care assess need and agree support levels and funding, so that the transition from children to adult services is as seamless as possible for families. For example we heard about some children where the level of financial support changed significantly when they moved to adult social care (both up and down) but the reasons why was not always clear for families. We have already started discussions with Adult Social Care.
- That we needed to ensure that services funded in universal settings, e.g. schools or children's centres and through our Local Offer are considered before any request for social care funding. This is to ensure that social care funding for children with exceptional needs remains targeted at those children who need it most and that services already funded are delivering what they are funded to deliver.
- That the services we provided did not always clearly link to an identified outcome so that we couldn't effectively review whether or not a service was actually making a positive difference and so that parents could understand how we have come to decide what money should be provided for what purpose, which is something they often complained about not understanding.
- That the particular circumstances of a family needed to be taken into account to allow for the fact that 2 families with a child with the same level of need might not need the same amount of support services. For example one family might be a mother who is a single parent with little or no support network locally, the other might be a 2 parent family with lots of family members in the local area. We need to make sure financial support packages take into account individual family circumstances.
- That we do not create services that are duplicated in other places, which if we combined into one place or commissioned through a single provider might cost us less. For example the provision of after school or holiday time activities currently happens in a variety of places and there is a need to review our commissioning arrangements in this area.

- That we identify if there are gaps in services. For example we have learnt through examining a number of children's current packages that there is a real need for home based parent focused training and support to manage the behaviour of children with autism at different stages of development (e.g. when first diagnosed, when becoming a teenager).

What we have done so far

We are having discussions with Adult Social Care to look at how we could align our resource allocation systems better in the future. We have examined approximately 40 children's budgets in detail in order to understand how we may want to commission some of our services differently in the future. We have a new Education Health and Care Needs Panel for children with severe and complex needs and so that the three agencies along with adult social care, can ensure that the finite financial support we have is targeting the right children and families at the right time, in the right ways and that it is making a difference.

Social Care plans presented to the panel should now be informed by the assessment and drawn up in partnership with families, evidencing clearly which people, services or things like equipment are going to meet which outcomes and to what level of intensity and it is this which will be examined by the Panel as it is asked to make funding decisions.

What we are proposing to do next

We are working with adult social care to look at ways to align better the way we make decisions about social care funding for families and will be issuing new practice guidance for staff in July 2015 to start to align practice whilst we then move on to review the resource allocation systems that we use to support financial decision making, again in partnership with adult social care.

2.3 Delivery of Short Breaks to children with Severe and Complex Needs

What we looked at

We looked at the way in which we commission short break services, these are short break services during the day as well as short break services that are overnight. These services are commissioned via Education and Social Care.

What we found

Day Provision

We found a really good offer of short breaks provision for Islington children and families. However we found that there was some duplication in what was being commissioned for out of

school day time activities but also some areas where families would benefit from some new ways of commissioning services that would potentially cost less.

Examples were groups of children with similar profile needs having activities to promote peer friendships using existing mainstream or specialist community based services (e.g. leisure services). For example if parents of teenagers who are also friends (as many attend the same special schools), could be given the opportunity to pool their budgets together (rather than each parent paying for their child to go somewhere individually where they then meet up) we could provide it as one service to them as a group, which should result in a cost saving e.g. on transport costs, level of supervision (e.g. if they do not all need 1:1 supervision).

We also found that lots of families needed to go through a social work assessment in order to access day time short break services which we believed was not necessary and so we want to look at whether we could make the access to some services easier for families for example through early help assessments and then linked into a child's Education Health and Care Plan if they have one in place.

Outreach Support

We found that apart from the outreach support that Lough Road were able to undertake on an ad-hoc basis where families were experiencing significant difficulties in managing challenging behaviour at home, this kind of service was not really working early enough with parents. The request to Lough Road was often made by the time children had reached adolescence and parents were really desperate and/or where social workers needed additional monitoring at home to understand to what extent the problems were to do with the needs of the young person and/or linked to possible concerns around parenting capacity and safeguarding. This was identified as a service gap in terms of the Local Authorities' ability to provide a service that could respond quickly and intensively to support parents and potentially also assist in informing social care assessments.

Overnight Provision

There are foster families who can provide overnight short breaks (family based short breaks) and we have Lough Road Centre (LRC) which offers overnight residential care short breaks.

The family based short breaks (FBSB) scheme has been developing and growing over the last few years to provide an increasing number of short breaks. In contrast, Lough Road has seen a significant reduction in the use of residential care short breaks (RCSB). In part this is due to the provision of family based short breaks but it is also due to the different ways parents are now able to choose their own ways of ensuring they have a break and they might choose to manage this within their own family network by paying a relative some money towards the cost of caring for their child through their personalised budget and this could be during the day or overnight.

A number of government reports and outcomes of inquiries about children's residential care, evidence that institutionalised care brings with it increased risks to children. An example relevant to children with severe disabilities is being exposed to multiple care givers. These particular children are extremely physically and emotionally dependent on their care givers. With multiple care givers this can render them more likely to suffer harm, for example with errors in meeting complex medical needs or the challenges involved in maintaining an individualised approach to the management of challenging behaviour.

It is already Islington's policy for looked after children that a decision to place a child in residential care should only happen where there is clear evidence that their needs cannot be met in a family setting and this principle must also apply to disabled children. If we cannot identify a suitable foster carer from Islington's approved pool of carers we would first seek to find a foster carer from suitably trained and approved providers in the independent sector.

The Government's Aiming High for Disabled Children's Initiative (2007)ⁱ resulted in increased funding for community based short breaks and this has had a really positive impact on families who have much more opportunities to have breaks in caring whilst their disabled child or young person is provided with activities to support them to access services in the community and/or to promote specific identified outcomes (e.g. independent living skills).

A needs analysis undertaken of the children at Lough Road who use it for overnight stays suggested that if we could find families with homes suitably adapted for children with severe physical disabilities and some families where there could be 2 carers at key times, all the children who are using it now who have complex physical health care needs (e.g. are physically disabled) could access that scheme. This seems obvious if one considers that all these children live with their own families when they are not at Lough Road in a family home environment. However the reality is that not many foster families have suitably adapted accommodation especially in an inner city area like Islington and so some children might need to either use a family that lives further away or continue to access residential provision.

There is a group of children who use Lough Road because they need a lot of support to manage very challenging behaviour, the vast majority are children diagnosed with profound autism. At the time we examined the young people in this cohort using Lough Road with this profile it was clear that they needed a residential service and for many the short breaks fostering service had not existed when they were referred to Lough Road.

However, when thinking about the future of children who will come to need these types of services we believe we can do things differently for some of these children. For younger children with profound autism, if we could introduce them to a foster family earlier in their life and slowly integrate some of their support being met there by promoting the relationship between the family and a foster carer as a short breaks day provision, we could then have the option to move that on to becoming overnight stays later on and we might then achieve a further reduction in the number of children who need to be looked after in a residential setting.

All this points to the likelihood of a reducing population of children who need to be in a residential setting and the need for an increase in family based short breaks, providing the families either have a house that is suitably adapted for things like wheelchairs and hoists or they are able to manage the ranges of challenging behaviours that children present with. It would be important to ensure that clinical support was easily available to carers, e.g. nursing support and/or Speech and Language Therapy.

What we have done so far

We have analysed the needs of children using LRC whether for day time or overnight short breaks or outreach support by meeting with managers from Lough Road and the Personalisation Team who support the setting up of personalised budgets. We have identified alternative possible resource options for every child to inform us more about how we might best provide services for them in the future. This has given us a picture about how to make the best use of existing resources as well as where there are gaps in resources that we should look to address in future. For example the support and training to parents in managing the behaviour of children with severe autism at home.

We have also identified a need for occasional counselling support to parents who may need somewhere confidential at different times of their children's lives to talk about the impact that having a child with disabilities is having on them. Many of the parents are single parents and quite a few parents have more children than just the disabled child to care for and the competing pressures and difficulties can feel quite overwhelming at times.

What we are proposing to do next

In light of the findings and plans in relation to Lough Road (see section 2.4) we will need to talk to parents of children using Lough Road to consider what other resources they might want to use in the future if Lough Road ceases to exist. This needs to happen as part of the formal proposal to now close this provision and all parents will be written to and have the opportunity to meet as a group as well as individually.

Our needs analysis and the outcome of our consultation with parents, will mean that we can use this information to also talk to existing providers (e.g. National Autistic Society and our Special Needs Schools) who may be able to offer more services to our children but we may also want to develop some new services in response to what parents suggest and the gaps we have already identified.

We also want to consult further with parents about the idea of an intensive home based parenting support service for children with autism, and we would like to involve them in the design and the commissioning of this kind of service.

2.4 Services for children at Lough Road Centre

What we looked at

We looked at the current provision of services at Lough Road Centre (LRC) in terms of the needs of the children who use LRC but also in terms of how LRC delivers the service and the cost of delivery. The needs information about the children was captured in section 2.3 above.

What we found

It is important to recognise that LRC has recently undergone a significant change in operations in response to the fact that the quality of care for children using it for overnight stays or who were living there permanently was being adversely affected for 2 primary reasons, this was also identified by an Ofsted Inspection in 2013.

1. Children who lived there permanently were sharing their home with children who were only there occasionally, vast numbers of children were using their home as a day care provision and sometimes children came in an emergency. This was not offering the children living there permanently the kind of environment that offered them a calm, stable and peaceful home environment.
2. Children using LRC can be broadly categorised in two primary need groups, those children whose primary need is to have their complex health needs managed (CHN) and those children whose primary need is to have their emotional and behavioural difficulties managed (EBD). The two needs are vastly different and mixing these children in LRC at the same time brings with it an element of risk to their safety and welfare. For example a severely autistic teenager who can lash out unexpectedly at others would be a serious risk to a child who is physically disabled and cannot remove themselves quickly enough out of the vicinity of that teenager.

As a result, the decision was made in December 2013 that once the last children left LRC for whom LRC was their permanent home, it would no longer be used as a long term home and that the 2 different needs groups would be catered for separately within LRC in future.

This meant that LRC had to re-organise how it delivered its services and parents were involved in discussions about the options for them when this change was made in April 2014.

However, the fact that LRC has a significantly reduced number of children using it for overnight stays and has made some operational changes to reduce the cost of running the service still means that the unit cost to providing this service to Islington's children is significantly above the average sector cost for this kind of service. In June 2014, with 12 children using Lough Road for overnight stays, one overnight stay at LRC cost £666.23 per night compared to the average private sector cost of £420 per night. The simple reason for this is that there is not sufficient need for overnight stays for Islington children alone to fill up the resource. If you add up all the children's bed nights that were used, LRC were only just about using 1 of the 6 beds available per year. The lower the occupancy the higher the unit cost.

Since June 2014 the numbers of children have reduced even more and we now only have 5 children using Lough Road for overnight stays (a further 50% reduction in less than a year) and 3 of those are young people who will transition over into adult services by November 2015, so that by November 2015 there will only be 2 young people using the overnight short breaks service. One of those young people is likely to move on very shortly to a more specialist residential provision and that would leave only 1 young person using LRC for overnight short breaks.

We do not anticipate any significant rise in the number of overnight stays that will be needed in residential settings in the future and estimate that for the next 5 years this will not rise above 120 nights per year in total.

The only way to reduce unit cost for a residential provision is to ensure that occupancy levels are high. This is not possible as the need is not there and as illustrated already, if anything we would anticipate our future need to be less or the same not higher with more children being able to use family based short breaks and not using residential care services.

Residential care has high fixed costs as it is difficult to use sessional or agency staff and respond flexibly to periods of high or low demand. There is a risk to the quality of care of the children if you have a flexible workforce model and the cost of investing in staff is high due to the specialist training they need e.g. physical handling, medication, some children require gastro (tube) feeding and the management of extremely challenging behaviour, there would be a significant cost in regularly training new sessional and agency workers. Therefore it is not possible to reduce the unit cost of residential provision at Lough Road to be in line with the average market sector based on current predicted needs levels.

A further staffing complication is the mixture of respite and day provision on offer, as this makes it even harder to reduce staffing costs as staff and managers are not just providing shift support to children using it for overnight short breaks and so potentially the resource is busy 24/7 requiring corresponding levels of management oversight and administration support.

When calculations were made in June 2014, the overnight short breaks service the annual cost for LRC was £198k per annum versus £125k using the private sector average cost for the number of children using it at that time. Based on the revised estimated level of need of 120 nights per annum that would now reduce even further to £51k (a cost saving of 147k per annum on the overnight provision).

The overall budget for LRC 2015/16 is £552,700. In November there will only be 2 children left using the overnight short break service, but the cost will still be £198k to provide the service this year, regardless of the number of children using it. Therefore if £198k is spent on children using it this year for overnight provision, the day time provision is costing £354,700 for 8545 staffing hours per annum, which is an hourly unit cost of £41.50. This is also significantly above average sector average and not reflecting what parents are being charged currently from their personalised budget which is £19.87 per hour. Therefore to retain the day provision would mean significantly increasing the hourly charge rate for LRC with the result that parents are likely to choose to purchase their services elsewhere.

What we have done so far

We have analysed the needs of all the children using LRC whether for day time or overnight short breaks or outreach support by meeting with managers from Lough Road and the Personalisation Team. We have identified alternative possible resource options for every child to inform us more about how we might best provide services for them in the future should the provision of services end or be changed in any way, this is without having consulted parents yet which would happen as part of the proposal to close this provision.

The only feasible way to retain LRC locally for overnight short breaks for our families and improve value for money would have been to secure a partnership arrangement with other Local Authorities who may wish to jointly commission a resource. Contact was made with our neighbouring borough commissioners and unfortunately the levels of need across the partnership is too low, particularly when Haringey, who have the biggest volume of demand, already have in-house provision and meets a much higher volume of need than Islington does. Haringey have no current plan to decommission their service.

We asked our colleagues in Housing and Adult Social Care to explore whether or not there might be a need for supported accommodation for young people transitioning into independent living. They conducted a needs analysis and reported that there would be insufficient need to require this type of resource.

We have consulted with the North London Children's Efficiency Programme (NLCEP) to explore what other need groups we could use this provision for as we know there is a real shortage of residential provision for non-disabled looked after children, and have identified that there is a need for a site to deliver what has already been signed up to by the 5 Borough Directors (Camden, Enfield, Haringey, Hackney and Islington) for its Government sponsored Innovation Projectⁱⁱ to create a short term residential provision for adolescents. £357k has been awarded to develop a service to become operational in Spring 2016.

Proposal for Consultation

Based on the findings of the review of Lough Road, the proposal is for services for disabled children to be ended at this site but for the site to be redeveloped as a short term (12 weeks) intensive/therapeutic residential service for adolescents who come into care across the 5 boroughs of the NLCEP with a focus on rehabilitation with their family or a foster family but avoiding the need for longer term residential care. These are adolescents who present with significant behavioural difficulties that are not disability related, e.g. behaviour that typically stems from difficulties associated with parent-child attachment problems, experiences of childhood trauma and/or abuse. Many young people will have no mental health diagnosis and some might be diagnosed with conduct disorder behaviour.

The budget provision for Lough Road will continue to be used for disabled children in order to:

- a) Commission overnight short breaks in residential care via the independent sector or if possible with other Local Authorities who still have such provision in place and where they are able to offer this to us.
- b) Commission short break day provision for the current children using Lough Road in ways that will be informed through consultation with the parents and children affected by this proposal, we want to use this opportunity to identify any further service gaps that we could use some of the money to fund.
- c) Commission a new intensive behaviour support / intervention service for parents managing children and young people with disabilities who display severe and challenging behaviour.
- d) Commission counselling support for parents and/or families who need space to talk about the impact of disability on them personally and/or their family and find ways to build and sustain family resilience.

There will be some savings to the cost of these services as a result of these proposed changes which will assist in funding the council's overall savings pressures whilst ensuring that the social care support needs of disabled children continue to be met in line with our statutory duty and preserving services such as our early support and proposed intensive behaviour support service to deliver effective early identification and support to families when difficulties start to emerge.

The proposal to end services for children with disabilities at Lough Road is subject to a formal consultation process including staff who work at Lough Road, families who use Lough Road and agencies who work in partnership with the services provided at Lough Road, e.g. The Disabled Children's Team, Special Needs Schools and Health Services. This consultation process will conclude in September and a final decision will be made by the Council's Executive Committee in November 2015. If the proposal is agreed then services are likely to cease as of 31/12/2015.



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ⁱ Aiming High for Disabled Children:
<http://webarchive.nationalarchives.gov.uk/20130401151715/http://education.gov.uk/publications/eorderingdownload/pu213.pdf>

ⁱⁱ DfE Innovation Project Grants:
<http://springconsortium.com/projects-being-funded/>