

Education, Children and Families Committee

10am, Thursday, 11 September 2014

Support to Children and Young People with Disabilities: Annual Progress Report

Item number	7.4
Report number	
Executive/routine	Executive
Wards	All

Executive summary

In October 2013, the annual report on Social Work Services for Children with Disabilities provided an overview on performance and planning in relation to support to families who have a child with a disability. This report is to update the Committee on the progress over the last year.

Links

Coalition pledges	P1
Council outcomes	CO1, CO3
Single Outcome Agreement	SO3

Support to Children and Young People with Disabilities-Annual Report

Recommendations

- 1.1 To recommend that the Education, Children and Families Committee:
 - 1.1.1 notes the progress made within social work services for children with disabilities
 - 1.1.2 requests a further report on progress in September 2015
 - 1.1.3 notes the progress on the expansion of School Holiday Respite Playschemes following implementation of service changes.

Background

- 2.1 The legislative base for the current provision of services for children and families affected by disability is underpinned by The Children (Scotland) Act 1995 to:
 - 2.1.1 minimise the effect on a disabled child within the authority's area.
 - 2.1.2 give these children the opportunity to lead lives as normal as possible.
 - 2.1.3 carry out an assessment of the child/young person and family.
- 2.2 The Social Care (Self-directed Support) (Scotland) Act 2013 came into effect on 1 April 2014. Self-directed support gives those children and their families who are eligible, control over a personal budget and allows them to choose how it is spent on support which meets their identified needs and agreed outcomes.
- 2.3 Self-directed Support offers four options for getting support. The person's individual budget can be:
 - 2.3.1 taken as a Direct Payment (a cash payment)
 - 2.3.2 allocated to a provider the individual chooses. The council or funder holds the budget but the person is in charge of how it is spent (this is sometimes called an individual service fund)
 - 2.3.3 or the individual can choose a council arranged service
 - 2.3.4 or the individual can choose a mix of these options for different types of support
- 2.4 The Children and Young People (Scotland) Act 2014 will provide further legislative support to work by focussing on improving outcomes through earlier support and joined up services.

- 2.5 Edinburgh's population is rapidly increasing compared to the rest of Scotland. By 2020 the number of children under sixteen, is set to rise by 16%, compared to 5% nationally.* Therefore depending on whether the definition used to define disability is within the Equality Act 2010, or relates to their additional support or social and emotional needs, then presently between 4,000-15,500 children or 5%-19%,(0-17) will have some type of disability.

*Care Inspectorate-Services for Children and Young People in the City of Edinburgh 29 April 2014.

Main report

Self-directed Support

- 3.1 The Social Care (Self-directed Support) (Scotland) Act 2013 came into effect on 1 April 2013. A report on the 'Progress on the Implementation of Self-directed Support in Children and Families' was presented to the Education, Children and Families Committee on 20 May 2014, in which it was asked to:
- 3.1.1 note the progress being made in implementing the requirements of the National Strategy for Self-directed Support and the Social Care (Self-directed Support)(Scotland) Act 2013, in respect of children and families.
 - 3.1.2 agree the approach being taken to the development of a Funding Allocation System to inform people of the indicative budget available to meet their social care needs.
- 3.2 The Council must implement the new legislation for all new referrals and all reviews of existing service users taking place after 1 April 2014. Existing service users will be advised of their rights under the self-directed support legislation, as part of the ongoing review process. It is envisaged that all existing service users will have been transferred to one of the four options of self-directed support within a period of three years from the implementation of the Social Care (Self-directed Support)(Scotland) Act 2013.
- 3.3 The approach which has been developed for children affected by a disability is to use a Funding Allocation System, which links the allocation of resources to the assessed level of an individual's need and the overall available budget.
- 3.4 The level of need is identified using both the revised current Section 23 Assessment of Need and Risk along with a new outcome focused Funding Allocation Questionnaire, which has been developed in line with the Getting It Right for Every Child well-being indicators (Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, and Included).The tool also allows the social worker to refine further their assessment of the person's level of need by matching them to a banding within the assessed level of need.
- 3.5 As there are no new resources available to fund self-directed support on an ongoing basis, the conversion of the score generated through the outcome

- focused assessment into an indicative budget, needs to take account of the budget available to meet the cost of providing social care support.
- 3.6 It is the budgets used to provide or procure these services now, which will be allocated to individuals through the Funding Allocation System. In many cases, people will use their personal budgets to procure existing services, although in the future it is increasingly likely that people will choose to access different forms of support.
 - 3.7 The first Funding Allocation Panel took place on 10 July 2014 and it is meeting fortnightly. Seven families have to date been given an Indicative Budget with which to develop a support plan.
 - 3.8 Despite the amount of work which has been undertaken to ensure the Funding Allocation System is calibrated to meet the needs of individuals and to be affordable, this is to some extent uncharted territory. Audit Scotland has recently identified as a risk for all Scottish councils the requirement to provide individuals with an estimate of the cost of meeting their care and support needs. This risk needs to be managed and monitored carefully.
 - 3.9 The implementation of self-directed support will have a significant impact on the shape of the social care market over time. Whilst it is difficult to predict the pace of change, the fact that the National Self-directed Support Strategy covers a ten-year period is an indicator that change is expected to be incremental, rather than immediate. However, it is important to ensure that mechanisms are in place to respond to the change required in a planned way.
 - 3.10 The introduction of the four options of self-directed support and the concept of personal budgets marks a move away from a service-led approach based on allocations of hours and nights to a more flexible notion of support where the currency is the amount of an individual's personal budget. As no new money is available to support this change, the Council needs to ensure that it is in a position to free resources tied up in existing services in order to be in a position to respond positively to those individuals who wish to use the resources available for their support in different ways.
 - 3.11 The Scottish Government has provided limited funds to assist with the implementation of the legislation. Monies have been used to develop a pilot service called the 'Drop In'. This will take place over five community centres across the city and will offer locally run activity sessions for families of children and young people who have a disability and who live in Edinburgh. The service is for children with a disability aged 0-18yrs, their parents and siblings. Parents are offered the opportunity to meet other parents while their children take part in activities run by experienced youth and children workers. This is a joint project delivered by Community Learning & Development and FABB funded by City of Edinburgh Council and hopes to be operational initially as a pilot project from October 2014.

Disability Practice Team

- 3.12 The staffing establishment (Full-Time Equivalent) within the Disability Practice Team consists of one Manager, two Team Leaders and 14 social work staff. The team undertakes assessments, support plans and other statutory duties relating to disabled children. The Hospital Team also carry a number of cases of children affected by a disability who would access our services. The current caseload for both teams consists of:

	Disability Practice Team	Hospital Team
Caseload	413	248
On Child Protection Register	6	22
Looked After and Accommodated Children	21	46
Looked After Children at Home	6	6

- 3.13 The table below details the current number* of children with a disability currently accessing our different service provisions:

Number of children currently receiving a service funded by Support to Children and Young People with Disabilities	739
Number of children receiving playscheme provision	400
Number of children receiving a day service	158
Number of children receiving overnight respite: in a residential setting	112 90 (80%)
in a family setting	22 (20%)
Number of children receiving a Direct Payment	24
Number of children awaiting a Section 23 assessment	45

*Figures correct as of 10 June 2014

- 3.14 The service has increased capacity in the Disability Practice team to reduce the numbers waiting for a Section 23 assessment. This is reducing the waiting list. However the new Self Directed Support legislation requires more intensive

assessment and care planning so overall demands on the Team remain high. We are currently investigating additional options to reduce waiting times for assessments.

- 3.15 The Disability Team has been receiving training on Emotions Talks and Talking Mats so that they can improve their communication skills with the children that they work with. Workers have used these tools to record children's views for Children's Hearings and for Reviews, and to help them to look at behavioural issues.
- 3.16 The Disability team works closely with the Health and Social Care Transition Team to move young people on from children to adult services. Further work is being progressed in looking at how we identify earlier young people who will require a substantial package of care into adulthood. In light of the implementation of self-directed support, the current jointly owned transition policy and procedures will also be reviewed over the next year.
- 3.17 A fortnightly emergency resource panel was established in May 2014 to deliver a speedier and joined up response to families in crisis and to assist in preventing family breakdown and, where appropriate, children having to be accommodated.
- 3.18 We continue to be challenged with the needs of young people with autism and a learning disability. The increase in playscheme support has been very helpful for most families but we still have a small but significant number of young people who require a high level of residential and day specialised support in the school holidays.
- 3.19 We work closely with the CAMHS Learning Disability Team who have an Intensive Behaviour Service. They offer many of our staff consultation sessions and behavioural strategies to ensure we can meet children and young people's individual needs. With the NHS we are currently reviewing our joint approach to ensure we maximise the benefits of the shared services we have and develop new initiatives in the future.
- 3.20 Many children with complex physical needs are now looked after at home. The children may need careful monitoring with interventions such as tracheotomy care, suction, catheterisation or tube feeding. The children benefit from being at home rather than hospital but the pressure on their parents/carers alongside family life can be considerable. This has led to an increased demand on council services. This pressure is also experienced in East, Mid and West Lothian Councils. We are discussing with NHS Lothian and local councils a joint approach on this growing pressure.

Organisational and Service Reviews

- 3.21 The Children and Families Occupational Therapy Team was established in 2006. This team was based until recently within the Children and Families service.

- 3.22 A service review took place last year involving both service delivery remits within this team - the Community Occupational Therapy Service and the Early Years Centres Service. The aim of this review was to improve service delivery to children and their families. Following the initial consultation period, it was the view that changes needed to be made to the whole team structure in order to improve the service delivery to children and their families, and to address the current level of demand and waiting lists within the Community Occupational Therapy Service.
- 3.23 As a result, it was the proposal that the Early Years Centre Occupational Therapy Service was transferred to NHS and this is currently in hand. For the Community Occupational Therapy Service, the proposal was that this service moved to the Disability Section of Health and Social Care, which it did on 1 April 2014.
- 3.24 An organisational review of Family Focus & Kidz Own began in June 2014 and will be completed by January 2015. The aim of this review is to address what changes need to be made to deliver greater choice and value for money, to children and their families. Consideration will also be on how these services will be delivered in the future, in line with the implementation of the Social Care (Self-directed Support)(Scotland) Act 2013.
- 3.25 The views of staff, stakeholders and families, children and young people will be sought on how we can deliver the best possible services to our families, efficiently and cost effectively. An Equalities Right and Impact Assessment has been carried out.

Playschemes

- 3.26 The Council, through the Early Years Change Fund, increased the funds available for Playscheme provision for children with a disability from £456,000 in 2012 to £812,000 in 2013/14. This was in response to views expressed by families in Edinburgh who found the school holidays problematic. The response to the increase in funding has resulted in positive feedback from families in Edinburgh. The initial proposals to expand Playscheme provision were reported to the Committee on 5 March 2013. The Committee asked officers to report back on progress after summer 2014, the first year of full implementation.
- 3.27 The contract for this new service was awarded to the INC Consortium which is made up of The Action Group, FABB Scotland, Lothian Autistic Society and The Yard. The new provision enables us to offer up to six weeks of playscheme service per year to 400 eligible children. The six weeks can be taken as four weeks in the summer, one week at Easter and either one week in February or October. The six week allocation may also include a residential camp or activity days.
- 3.28 370 families applied for the playscheme service this summer, some applied for less than the number of weeks available to them. Research undertaken by the

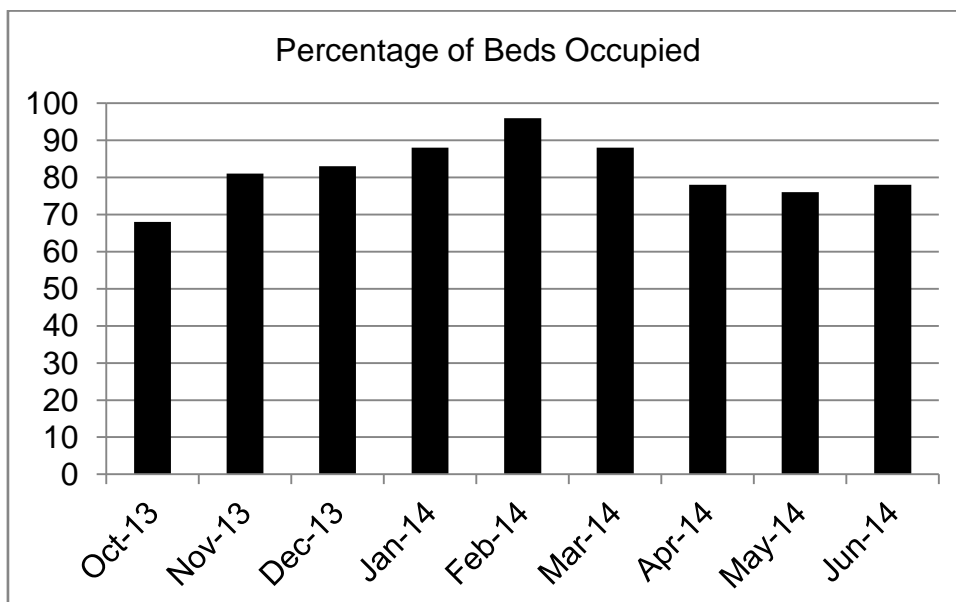
four venues indicated the following reasons for families not accessing their full quota showed the following:

Reason	Number of Families	Percentage
Cost	15	23
Pre-booked family holiday	18	28
Unsure if my child would cope	6	9
Playscheme is new to me, need to try it out first	9	4
Other	17	26
Total	65	100%

- 3.29 We also ran a small playscheme service at the Action for Children resource in Gilmerton Road. The young people involved in this service need to be on their own or in a very small group. Four children who would not manage at the disability playscheme attended this service successfully.
- 3.30 We plan to appoint a Playscheme Co-ordinator to overview the day to day running and to link into the schools involved, so that good communication is shared about individual children's needs with the sector providers.
- 3.31 A detailed lessons learned session involving the views of children and families will be held to monitor the delivery of the new contract and to consider possible improvements for year two of the contract.
- 3.32 Discussions have begun with Edinburgh Leisure for the provision of family drop in swimming sessions. We hope to be able to offer this activity in February/Easter 2015.

Hillview

- 3.33 Hillview is a small five bedded residential resource that is used for families who require crisis provision in Edinburgh. The majority of children who attend Hillview are there because there is no other placement available to them in Edinburgh. Some children stay for a short time and others for many complex reasons remain for between six months to a year. The crisis nature of this service is that they have to respond quickly some times during the night due to issues such as sudden illness in a parent/carer. On occasions we are able to offer short breaks to families who are having adaptations in their house which means their child has to be cared elsewhere with access to hoists and appropriate bathroom facilities.



3.34 The residency rate is high and varies from 70% to 90% (see table above). When this figure is lower this is due to the complexity of care involved in a mixed group of young people with disability needs. For example there may be three or four young people in wheelchairs which will involve a high level of personal care support from staff or we can have a young person with very challenging behaviour in a group of vulnerable young children so these factors can influence the ability to use all of the available beds.

3.35 The disability family support service, which is based at Hillview, started on the 25 May 2014. This new service consists of three full time Social Care Workers who provide a city wide, seven day support service from 7am to 9pm. They offer families crisis support in the home or in the community for between 6-12 weeks.

3.36 The service supports families with children who may otherwise be accommodated due to child welfare concerns, parent/carer sudden illness/ exhaustion or rehabilitation to home from care settings. We will be able to give qualitative information within the next annual report about the impact and value of this new service.

Barnardos Intensive Behavioural Support Service (BIBSS)

3.37 The City of Edinburgh Council continues to fund the learning disability element of Barnardos Intensive Behavioural Support Service (BIBSS), with funding for the autism element coming from the Scottish Government's Autism Initiative which will come to an end in March 2015.

3.38 During the period April 2013-14, Barnardo's Intensive Behaviour Support Service had 45 children referred to its service. Nineteen had learning disabilities and 26 had autism but no learning disability. Over this same period the team worked with 29 families who had a child with learning disabilities and 13 with autism only totaling 42 families altogether. The waiting list currently stands at 27 families-12 with children with learning disabilities and 17 with autism only.

- 3.39 The disability behavioural support service started on the 13 Jan 2014 and complements and works in partnership with the aforementioned BIBSS Service. It is part of a two year project funded by the Early Year's Change fund. It employs two project workers who work with parents/carers in managing their child's behaviour. It offers a time-limited service for up to 12 weeks and provides a city-wide service to children/young people age 4-16 years.
- 3.40 The aim of the service is to improve parents/carers confidence and resilience, reduce stress and improve family relationships and help provide a better understanding of the child's/young person's disability/autism.

Seaview

- 3.41 For the last few months staff at Seaview have been preparing to manage the significant changes which self-directed support will bring. Seaview currently offers fixed groups and respite times, which in turn offers consistency, familiarity and an opportunity for children and young people to make friendships and share activities.
- 3.42 The challenge is to retain as much of these values as Seaview can, whilst offering families greater flexibility, and managing variable packages of care dependent on assessed need. This will enable families to have greater flexibility and choice as to when they have their short breaks. An electronic booking system has been installed to assist with some of the practicalities.

Family Focus

- 3.43 Family Focus started a group for children under five with sensory and communication difficulties in October 2013, who are or may be diagnosed with autism, and their families. This programme is funded by the Scottish Government's Autism Strategy until 2016 and runs in eight week blocks. It aims to promote and develop children's sensory integration, interaction with other children, attachment between parents and their children, and parental confidence.
- 3.44 The outcomes and feedback from the groups has been overwhelmingly positive with significant improvements in the abilities of every child, increased parental confidence and ability to interact and manage their child.

Strategic planning

- 3.45 A strategic planning group reporting to the Children's Partnership has been formed to take forward multi-agency planning of services for children with disabilities. The vision is for our children and young people with a disability to have improved life chances and the support required to fulfil their potential. We will do this by:
- 3.45.1 leading the development of services and support which meet the needs of these children and young people in pre-school, education, care, health, leisure and family settings.

- 3.45.2 improving consistency in the quality and availability of provision.
 - 3.45.3 establishing robust baseline information about the number of children and young people with a disability, the range of disability and the services provided.
 - 3.45.4 monitoring performance against our agreed objects and reporting back to the Children's Partnership.
- 3.46 The overriding objective will be to produce a plan and performance framework for disability services in the coming years with outcomes to be included in the next Integrated Children's Services Plan. The focus should be on children with a disability achieving their potential, using the same Getting it Right for Every Child wellbeing (SHANARRI) assessment outcomes for all children.

Measures of success

- 4.1 Meeting the requirements of the Social Care (Self-directed Support)(Scotland) Act 2013 which will be evidenced by:
 - 4.1.1 compliance with the principles underpinning the legislation.
 - 4.1.2 the ability to offer people who are eligible for social care support, the four options as to how that support is organised and managed.
 - 4.1.3 the ability to notify people eligible for the four options of self-directed support of an estimate of the cost of meeting their care needs and support needs.
 - 4.1.4 the emergence of new types of services to meet care and support needs.
 - 4.1.5 all eligible children having a self-directed support plan by April 2017 from which to measure outcomes rather than outputs.
- 4.2 The Council achieving a reduction in the waiting times required for a Section 23 assessment.
- 4.3 The number of children with a disability having to become fully looked after and accommodated reduces.

Financial impact

- 5.1 The implementation of self-directed support across Edinburgh is regarded by the Scottish Government as cost neutral. There will be work load pressures in the implementation of this new way of working particularly in the Disability Practice Team. The service is currently reviewing the resources available to support the implementation of self-directed support with the aim of addressing the expected increased demands on practitioners.

Risk, policy, compliance and governance impact

- 6.1 The implementation of the requirements of the Social Care (Self-directed Support)(Scotland) Act 2013 requires a change in the way in which support is currently provided to children, young people and families eligible for assistance. Rather than providing or arranging services to meet the assessed need, the Council is required to provide to families an estimate of the cost of meeting their social care needs and to then support them to exercise as much choice and control as they wish in meeting these needs, within the resources available. Over time this will lead to significant change in the range and types of services available.
- 6.2 The operation of the Funding Allocation System will be closely monitored to evaluate the following factors:
- 6.2.1 The Funding Allocation System is sufficiently flexible to be adjusted in response to issues identified through experience in operating the system.
- 6.2.2 The Funding Allocation System is calibrated in order both to meet the needs of individuals and remain affordable to the Council.

Equalities impact

- 7.1 The fundamental principles of self-directed support are choice and control, enabling people to choose how to live their life and have control over the way in which their care needs are met. The Social Care (Self-directed Support) (Scotland) Act 2013 seeks to ensure that the principles of human rights and equality are central to the delivery of social care by placing a duty on local authorities to have regard to inclusion, collaboration and dignity when carrying out their duties. This report gives some detail to the manner in which it is proposed that these principles are embedded in Edinburgh.
- 7.2 There is an overall Equality Rights Impact Assessment (ERIA) which has been completed in respect of the Personalisation Programme. An overall Equality Rights Impact Assessment has also been completed for the recently completed review of the Children and Families Occupational Therapy Team and for the organisational review of Kidz Own and Family Focus.
- 7.3 An ERIA summary report for the Committee has been completed, summarising the above (see Appendix One).

Sustainability impact

- 8.1 The impacts of this report have been considered in relation to the three elements of the Climate Change (Scotland) Act 2009 Public Bodies Duties. There are no sustainable impacts in relation to the contents of this progress report.

Consultation and engagement

- 9.1 Parents and carers of children with disabilities who currently receive a service were invited to consult on self-directed support, service provision and related issues in January 2014. The consultation consisted of an online/paper survey and three focus groups. Parents/carers were contacted by letter, through a newsletter and through partner agencies and providers. A total of 52 parents/carers responded to the online survey and 30 people attended the focus groups. Some people attended a focus group and completed the survey.
- 9.2 It is recognised by the Scottish Government and Audit Scotland that the implementation of the self-directed support legislation will take time and will continue to be developmental. In order to support ongoing consultation a Parents/Carers Checkpoint Group has been established. It is proposed that the group will meet on a regular basis to discuss matters in relation to self-directed support and service developments.
- 9.3 A newsletter has been developed and issued on a four monthly basis through a school-bag drop to all children who receive special or additional education services. The purpose of this newsletter is to keep children and their families up to date with self-directed support and service developments.
- 9.4 There have also been regular engagement and consultation sessions, over the past year, with providers who support children with a disability in Edinburgh to aid the implementation of self-directed support and facilitate forward thinking in promoting a diverse and flexible market place for children and families in Edinburgh.
- 9.5 The views of staff, stakeholders and families, children and young people will be sought accordingly during the organisational review of Kidz Own and Family Focus, as to how we can deliver the best possible services to our families, efficiently and cost effectively.

Background reading/external references

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Links

Coalition pledges	P1 – Increase support for vulnerable children, including help for families so that fewer go into care
Council outcomes	CO1 – Our children have the best in life, are ready to make and sustain relationships and are ready to succeed CO3 – Our children and young people in need, or with a disability, have improved life chances
Single Outcome Agreement	SO3 – Edinburgh's children and young people enjoy their childhood and fulfil their potential
Appendices	1 ERIA Summary Report for Council Decision Makers

ERIA Summary Report for Council Decision Makers

What CMT report / Committee report (including meeting date) does this ERIA information relate to?

Annual Report to Education, Children and Families Committee on support to children and young people with disabilities – 11th September 2014.

ERIA assessments have been carried out in relation to:

- Progress on the Implementation of Self-directed Support to Education, Children and Families on Self-directed support – 20th May 2014
- Review of Children & Families Occupational Therapy Team – 5th June 2014
- The Organisational Review of Family Focus and KidzOwn – 9th July 2014
- Personalisation Programme City of Edinburgh Council August 2014 - in progress.

What are the main impacts on rights?

Health – a variety of support services will be available to enhance the wellbeing of children and their families through services ranging from behavioural support, to day activities and overnight respite.

Life - to enhance the social opportunities open to children and their families, through inclusion in services which will promote their wellbeing and participation in community services accordingly.

Participation, Influence and voice – our services offer children a voice by actively seeking their views in relation to their participation and/or any plans made in relation to their wellbeing, whenever appropriate and possible for them to do so.

Deliver more appropriate services to children and their families as a result of their engagement and through seeking the views.

Productive and Valued Activities – access to a range of services that support service users to feel valued and included i.e. play schemes, that enhances their quality of life and allows them increased opportunities for play and social inclusion.

Individual, family and social life – to enhance access to social opportunities, thereby supporting children and young people to live safely at home with their families.

Self-Directed Support will enhance equality by ensuring that service users are treated fairly and equally, and this is done specifically to their needs and from this, care packages will be developed on an individual and person centred basis.

Identity, expression and self respect –our services support children and young people to live with their parents and to improve their sense of worth, dignity and respect. The implementation of Self-Directed Support will also assist with this, as it promotes the personalisation of services to meet their agreed outcomes.

What are the main impacts on equality?

Improve opportunities for social integration, thereby reducing ignorance and prejudice surrounding some disabilities, by offering service users a more person centred approach to the delivery of their assessed needs.

What are the main ERIA recommendations?

1. Changes to our recording systems, enabling statistics on poverty, ethnicity and gender to be collated over the next three years. Our section 23 assessments already use an income maximisation section to improve uptake of welfare benefits.
2. Key performance indicators identified in relation to self-directed support for children and families during the next three years. Lead officer and timescales have been identified.
3. Children and Families are evaluating the use of the Funding Allocation System and will be monitoring uptake of the four SDS options. Lead officers identified, and Service Manager reporting back to the Education, Children and Families Committee in May 2015.
4. Clear communication plans with service users and stakeholders affected by the reviews of the Occupational Therapy Team and Family Focus & KidzOwn. Lead officers identified and timescales agreed.
5. To support practitioners within Council to achieve a balance between people's rights to take risks and harm minimisation, a Risk Enablement Framework be developed that incorporates the FAIR (Facts, Analysis, Identification & Review) approach to human rights into the assessment and support planning process. Lead officers and timescales to be agreed by H&SC colleagues who have the lead in relation to this.
6. To improve the Council's ability to publish equality outcomes and report progress, given the existing gaps in data and need to monitor experience of self-directed support implementation, integrate equalities monitoring into a Personalisation Programme Performance Management Framework. Lead officers and timescales to be agreed by H&SC colleagues who have the lead in relation to this

Further Information (name / position / contact details):

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