

**Aiming High for Disabled Children**  
**Parent/Carer Consultation on Eligibility and the Transition Protocol**  
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**Context:**

EnhanceAble was charged to facilitate a consultation on aspects of the local Aiming High for Disabled Children's Agenda.

- “Eligibility” with specific reference to access to services funded by Aiming High
- The local “Transition to adult services protocol”
- Additional research questions were posed regarding:
  - ❖ current services within the Royal Borough
  - ❖ how parents wished to be consulted in the future

An event was held on the 12<sup>th</sup> of December when presentations and workshops were delivered providing parents and carers present the opportunity to air their views. Please see attached the interim review report on that event.

So as to offer the opportunity to a much wider group of parents a paper questionnaire was sent to the 382 parents on Kingston's “I-Count” Register.

This report analyses the responses to the questions posed from the two groups.

382 Invitations were sent to all the parents/carers who have a child or children on the Kingston “I-Count” Register - and in addition another 50 invitations were sent out to parents who are registered with the DCIAS to attend the event on the 12<sup>th</sup> of December – 16 parents attended.

This level of distribution was repeated when the paper questionnaire was disseminated in January.

Parents/Carers were sent the paper version of the consultation in early January 2010 and were given until the 12<sup>th</sup> of February to return their views.

The reply rate to the paper questionnaire was disappointing at only 6.02%, but adding these responses to those received from the Consultation event provides a 10.21% level of parent/carers feedback.

## **Eligibility**

Parents/Carers were presented with the draft Eligibility criteria for accessing services being funded by the Aiming High for Disabled Children Programme in Kingston.

### **Aiming High for Disabled Children Eligibility Criteria for Children/Young People Aged**

#### **0 – 19<sup>th</sup> Birthday**

The following eligibility criteria have been developed to promote transparency, consistency and equality.

The Royal Borough of Kingston upon Thames (RBK) will be consulting on this framework with parents/carers of disabled children/young people.

This document will form the basis for access to short breaks in RBK.

Locally, all disabled children/young people are eligible to access relevant community, leisure or support services delivered via Advancing Services for Kingston Kids (ASKK), Moor Lane Children & young People's Development Service, Integrated Youth Support Services (IYSS) or our partner agencies.

National eligibility criteria guidelines are currently being developed. RBK will re-visit the local eligibility criteria and amend if required.

#### **What is a Short Break:**

- Sessions in After School Clubs, Activity Groups, Clubs and Day care settings
- Support in accessing activities in universal settings
- Overnight breaks with care available in both the child/young person's own home and elsewhere

Breaks during the day, with care available in the child/young person's own home and/or in the community

#### **Short Breaks will:**

- Promote friendships and involvements in social activities and new experiences
- Provide culturally appropriate provision for the child/young person and their families
- Be planned, regular and at times to suit the child/young person and their families wherever possible

Be age appropriate

#### **Pathway 1: Universal Short Breaks (Levels 1 and 2)**

- Open to all disabled children and young people
- Access to mainstream leisure provision and universal services
- Referral direct to provider

Referral support available if required via ASKK Service, Extended Services Managers, Children's Centre Managers

## Pathway 2: Universal Short Breaks, with Support (Levels 2, 3 and 4)

- Open to all disabled children and young people
- Supported into mainstream leisure provision and universal services
- Support from a worker can be provided for set period of time
- Specialist training can be provided for provider staff
- Specialist equipment can be provided
- Referral via Inclusion Officer or Social Worker

## Pathway 3: Specialist Short Breaks (Levels 3 and 4)

- Open to all disabled children and young people who have been assessed by the Disabled Children's Team
- Referral via Social Worker

<b>Disability</b>	<b>Mild Level 1</b>	<b>Moderate Level 2</b>	<b>Severe Level 3</b>	<b>Profound Level 4</b>
Learning	Attends mainstream school / pre school	Attends mainstream school / pre school with limited support	Attends special school / pre school for children with severe learning difficulties	Attends special school / pre school for children with Severe / Profound Learning Difficulties or specialised autistic unit with full support
Mobility	Some limitations of function/poor co-ordination	Able to walk. May require aids some of the time	Unable to walk without aids. Unable to manoeuvre and / or transfer without support	Wheelchair user. Fully dependent on others for mobility
Health	Known, controlled health condition which causes minor disruption to daily tasks	Health needs limit ability to perform everyday tasks. Learning not affected	Health needs have a significant impact on development and learning	Complex health needs prevent participation in social and educational activities
Personal Care	Some difficulty meeting own personal care	With supervision, can engage in personal care	Requires assistance for all personal care	Dependent on others for support for all personal care

	needs			
Seizure activity	Occasional seizures	Regular seizures	Regular seizures which impact on the child or young persons learning and development	Seizures in frequent succession unable to be controlled by medication
Challenging behaviour associated with disability	Behaviours that can be difficult to manage at times	Behavioural or management difficulties which may require specialist advice or support	Challenging behaviours which impact significantly on community life and requires specialist provision to function socially / educationally	Severe Challenging behaviours which impact on all aspects of the child / young persons functioning or pose a significant safety risk to self or others
Safety	Occasionally requires more supervision than children of the same age	Needs some supervision at times.  Limited perception of danger to self or others	Requires greater supervision than children of the same age	Needs constant supervision. Doesn't perceive danger to self or others
Under 5's		Functioning moderately behind the level expected for age		Significant failure to meet developmental milestones
Visual / Hearing Impairment	All children/young people with visual or hearing impairment are eligible for an assessment in conjunction with Adult Services			

## **Parent/Carer Feedback:**

In addition to the comments to the questions posed made by those parents and carers who attended the consultation event (see attached Interim Report) those who fed back in writing provided the following information.

### **Are the criteria clear in their current format?**

43.47% of those who responded felt that the criteria in their current format were clear, 26.09% stated that the criteria were not clear and 30.44% gave no feedback.

Additional comments made were:

- Does a child have to meet all the criteria to qualify for services?
- Who makes the final decision as to what level a child is placed?
- Parents should have the right to observe activities
- Need to add Communication Difficulties as a specific disability
- Eligibility was clear but misleading
- Safety criteria are muddled
- Why only two levels for the under 5's
- Learning levels are not accurate
- Fairly clear but some issues

### **What should be done to make them clearer?**

- State clearly how the criteria will be applied to each child. Where there is a mix of criteria i.e. mix of different levels, who makes the decision as to the level of support the child is eligible for?
- Assessments re eligibility should be done by parents and professionals who know the individual child
- How do you get an assessment?
- Rewrite safety: all levels to include "Requires greater supervision than children of the same age".
- Learning needs – more explanation at each level
- Where are the children attending special schools for moderate learning difficulties or attending specialist schools for Social Communication disorders but with average learning abilities?
- Should be made clear that some criteria do not apply to all children i.e. seizures and mobility
- Under moderate/learning – I believe that this should include children in special autistic units i.e. The Mount
- "Limited support" sounds too little for some e.g. children in mainstream with fulltime 1:1 support – this is more than limited
- Description of the different pathways are confusing. Can they be re-written in more everyday language

- What does universal services mean
- What does referral support mean – 2 parents highlighted this
- What is being provided under Pathway 1 that would make a difference or make it more inclusive
- Even a child on level 1 would have a significant impact on what can be done as a family. Impact on siblings should be considered – a level 1 child still requires a short break to allow other children some “normal time”
- Instructions on how to go about finding out where your child falls and if you need to get them assessed. For example if we find a club we want our child to attend what do we do next?
- Clarity is a problem. Process seems to “pigeon hole” children.
- Who decides what level a child is assessed at?
- Headline/title does not make clear this is about eligibility for short breaks.
- Some parents may be confused by the grid, thinking their children are only eligible if they have all the listed disabilities at a particular level

## **Transition Protocol**

### **Consultation with Parents/Carers**

#### **on the Transition Protocol**

In addition to the points raised at the consultation event (see interim report) parents provided the following feedback:

30.43% of those who responded to the consultation have children who are not old enough to have accessed the Transition Service so were unable to provide feedback on some of the questions to do with current access to the Transition Service.

#### **Questionnaire:**

The Transition Team are presently developing a transition protocol for young people aged 14 plus , which is a strategic document that details the roles and responsibilities of all agencies in the transition process. To ensure that the protocol is relevant, realistic and effective, your views in devising the protocol would be much appreciated.

Please answer the list of questions below to help you make a contribution to the protocol.

**1. If you have a child aged 14 plus how have you found the transition planning process for your child to date?**

- There was not really a Transition Plan to help leaving school and transferring to college. We were left to select a college we felt was right for ourselves
- There has been no planning or involvement from RBK in our son's transition to date – he is 15
- Good
- Child 1- Although my child was well known to Social Services and Education, so they knew very well what service was required post-transition finding a suitable residential placement was still haphazard last minute and stressful. This is due to a lack of National co ordination, planning etc, not local.  
Child 2 – Transition process only been active for about 18 months so difficult to say. Not particularly impressed so far from education but local (out of borough) Connexions Advisor has been very good.
- Non-existent –while there may have been background activity it has always been down to us to push things forward.
- Unaware of any transition planning process
- Planning within the school was good but as my son's school was out of borough there was no link to the appropriate RBK agencies. Planning has only taken place Post 16 due to the intervention of the Transition Worker.
- My son is almost 17. I was given a list of provisions when he was 15. Nothing since. Hope to meet the Transition Worker soon!
- I haven't been aware of it.
- Not had any as yet

**2. What do you feel is working well in the current transition planning process?**

- I suppose identifying for my daughter that she had the academic ability to consider further and higher education, but her GCSE results reflected that too – all A and B grades.
- Nothing x 3
- Connexions Advisor has been helpful and knowledgeable. Education Dept not so good, but school very helpful also.
- The only thing working well is the transition worker who has personally intervened and has been instrumental in making links and identifying appropriate services and agencies
- School links with Merton College

**3. Is there anything you feel needs to change in the transition planning process? If yes, please provide details of what changes you would like to see?**

- An opportunity for SEN children to visit colleges on a special arrangement. General open days are chaotic and I could only persuade my daughter to visit one. It was such a traumatic experience for her that she wouldn't visit any others. When I asked colleges if we could make special arrangements they said "no" and if she couldn't cope with Open Days than she should not be considering college!
- No
- More advice on options beyond transition. Often it seems to be left entirely to parents to find what is available.
- Contact with parents
- Clear communication about what it is and who it applies to.
- Young people need to be identified and planned for and not be allowed to fall through the net.
- More contact
- More independence

**4. Would you like an information pack on transition to be sent to you when your child reaches the age of 14? If no, when would you like to have information on transition?**

82.61% of those questioned requested an information pack.

13.04% stated that it was too late now as their children are much older than 14 but it would have been a good idea in hindsight.

8.69% felt that 12 was a more appropriate age to commence receiving information on Transition.

**5. What information would you like on Transition?**

- General info on courses available. Outline of what the college provides for SEN students.
- Education, employment, accommodation, leisure, benefits, advocacy
- Names, contact numbers of personnel agencies that can advise or who may be relevant
- Schools and help available, what experiences others have had. Meetings with support workers and schools.
- How to help my child deal with Transition
- Career path/choices help. Connexions have been diabolically poor.
- Clear communication about what is available

- What agencies are involved, what they do i.e funding, support, extra curricular
- What it actually means in regard to a child who turns 14
- Everything there is to know x 3
- Social groups and clubs. Travel training.

**6 Which agencies and/or professionals do you feel should be party to this protocol and involved in the transition process?**

- A Social Services Transition worker would be helpful at Educational Reviews.
- Any professional help is a bonus because you need objective views.
- Schools, Education Department, Social Services
- Our experiences are agencies have been useless diluting responsibilities
- Health professionals including GP, special needs schools
- Any that can influence the process or who can contribute to smooth transition
- Schools and Social workers
- Connexions
- Team for Disabled Children x 2

**7 Would you like more joint working between Adult and Children's Services and what do you think this would entail i.e. what are your expectations of Adult Services and Children's Services?**

26.92% of those who responded wished for more joint working between the two services, 8.69% were unsure and the remaining 64% did not respond to the question.

- We want a clear cut off date between Children's and Adult Services e.g. 16<sup>th</sup> birthday. We want a one stop shop where all our issues regarding education, employment, accommodation and benefits are dealt with by one agency.
- Details of courses, clubs, activities and information
- We have had such little contact it is hard to say
- To provide appropriate support when needed
- I want to know where responsibility starts and ends. Funding implications and the management of the Statement of Educational Needs
- More information available on request. Clear communication
- How the two will differ and what we will lose from Children's Services and gain from Adult Services

**8. Can you suggest any new ways of completing the transition plans and linking this to the educational reviews?**

- Transition Worker interview with child and parents which is then included in Educational reviews
- Attendance at Annual Reviews would be a start. You may build an understanding of the individual
- Our son is in private education so this would not help
- I haven't experienced the old way. A key RBK person should be involved in educational reviews to identify issues and feed into the process

**9. What do you think should be the priorities when undertaking transition planning?**

- To know exactly what services we will lose and when. What we are entitled to from adult services
- Parental involvement. Involvement of young person and support for the pupil
- Contact and full explanation of what is available etc.
- Identifying key people and agencies. Responsibilities. Options – identifying what is possible. Funding implications of choices
- Child get as much continuity and support as possible
- Ample time
- The child's well being, looking into possible career planning and how to be prepared
- Making sure of the happiness and welfare of the child is the most important thing.
- That the child is fully aware of the options and services available so that they together with parents can make informed decisions.
- Clarity and openness amongst all parties so that the child's needs are fully understood by all and provision is accurately described and delivered.
- Access to information regarding education, employment, housing, leisure and benefits post 16 years. Who is going to be our son's advocate post 16 years?

## 10 Any other comments

- I need to ensure that my son receives all the support he needs and what he is entitled to from RBK during the transition and adult services. I need someone independent from RBK to provide this.
- Health could play a greater role in transition too as services for adults are not anywhere near as good as for children. Parents need to be forewarned of this and relevant Health Agencies should have information to make the change over easier and more efficient.
- More transparency in RBK is good but sometimes information is hard to get in the first place
- My experience of the transition process was poor. It has been changed only to the effort and commitment of the transition worker who came on board post transition.

### Additional Questions:

#### 1. What services would you like to see more of in Kingston?

- Respite and activity centres
- More information on current services
- Social activities and groups – any currently available are for more able children
- Specialist short breaks
- Support to enable young people to access mainstream leisure activities and facilities
- Services for teenagers – competitive sports, mentoring and film nights
- Sensible OT services – including sensory OT
- More playgroups (after school) for 5-8 year olds
- We have seen very little so it is hard to say anything
- Saturday and holiday clubs that do not need parents to stay or can only be accessed by family support workers
- Youth clubs for the under 12's. A better flow of information from your GP to Children's Services to school.
- If this question includes those services provided by the NHS than Speech and Language Therapy, Physiotherapy and Occupational Therapy.
- Share the care, Family support etc to allow parents to do "normal things with siblings.
- Leisure activities designed for disabled children e.g. horse riding, dance clubs, swimming etc. open to the under 8's.
- Groups for young adults with Asperger's/Social Communication Disorder/High functioning ASD.

- Sports activities for disabled children.
- More information on what is available
- Support for siblings
- More afterschool or holiday clubs. Yorda Adventures are fantastic but their priority is for the more severely disabled child. We need something for children who are "mildly" disabled.
- Counseling for parents
- More family support and specialist baby-sitting services
- Specialist play schemes for the more able child.
- Support during the holidays for older children 11-18 with working parents.
- Social skills communication groups for the under 8's.

## **2. What services has your child or young person found useful, helpful or fun?**

- So far I have been unable to find any service suitable or convenient for my child. X 3
- Nothing. We have had to make private arrangements for clubs etc
- Babysitting service, weekly family support to enable him to attend Boys Brigade and Tigers.
- Clubs for 14+ and 16+ x 3
- Equal access to the afterschool clubs mainstream children are offered with additional support
- Trampolining at the Tolworth Centre but it is only four weekly.
- Trampolining and other sports activities.
- Activities group for adolescents with Asperger's have been really valuable for my son.
- SWAPS Sunday Fun Sessions
- Portage Communication Group
- Portage
- Mainstream swimming – but this was only up to Mother and Toddler age
- Fun Days – where children and parents can relax and be themselves.
- Asperger's United
- Family Support Services
- Yorda Adventures
- Challengers
- Play activity Groups
- Social Services
- Disabled Gym sessions at Tolworth
- Physiotherapy x2
- I-Count Card
- London Youth Games
- Respite weekends

- Kingston Holiday Club x 2
- Speech and Language and Occupational Therapies
- Warren Park

### 3. What mainstream service would you like your child or young person to access?

- More information
- Specialist respite breaks, horse riding, specialist holiday clubs, family support
- Help to support accessing hobbies
- Activities that help develop competitiveness and raising of self esteem.
- Sports facilities and coaching
- Supported play groups
- Social and leisure activities
- Trampolining
- Afterschool clubs x 3
- Holiday clubs
- Computer, chess, engineering, Lego clubs.
- Swimming – only one to one options available at the moment x 2
- Cubs/Brownies
- Dance
- Mainstream holiday clubs should be more flexible for disabled children
- More help for working parents during school holidays
- Equal access to mainstream afterschool activities – support needs to be provided

### 4. How would you as parents/carers like to be consulted on services and development in the future?

- Mail – **13.04%**
- Borough wide electronic survey
- Meetings – **8.69%**  
Regularly
- EnhanceAble
- Mencap
- Social Services
- Questionnaires – **21.74%**
- Information Days – **13.04%**
- By any means and frequently – however there does currently seem to be lots of consultation but not much action
- Web based consultation – 8.69%

- We don't want to be "nannied" but should still be involved and not just via parents support groups
- Telephone Interviews

## **Conclusion**

**The results from the consultation day on the 12<sup>th</sup> of December tally with the results of the paper questionnaire. Parents have some issues with the Eligibility Criteria document in its current format but this is already being addressed by officers from RBK with the information gleaned from the consultation day.**

**The Transition Protocol and the perception of the services received from the Transition Service are clearly of concern and frustration for parents/carers. A lack of understanding and consistent service delivery seems to be the main source of concern.**

**The parents/carers who responded with reference to additional questions posed suggest that while they are happy in general with the varied programme of activities and opportunities available for their young people. There is a strong desire for an increase in the amount available, in particular specialist activities, for young people with moderate learning difficulties and those presenting with Asperger's and High Functioning ASD.**

**Parents via both consultations clearly want to take an active part in the development of services and wish to be consulted in a wide range of ways. The parents who are members of the Kingston Web Forum have also been canvassed on this topic and there is a clear wish to see the Kingston Parents Panel re instated as soon as possible.**

**There is a good resource of parental knowledge and skill available to be utilised in Kingston and that resource is keen to be a part of the plans for future development.**

