

REPORT TO HEALTH AND WELLBEING BOARD

Title: The Transitions from Children to Adult Health and Social Care

Date: 15 July 2011

Member Reporting: Cllr Dudley and Cllr Quick

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Wards affected: All

1. SUMMARY

- 1.1.1 This report summarises the approach taken recently to improve the long term care and support that is developed for and with children, young people and their carers. The approach being developed involves the Primary Care Trust (PCT), Children and Adult Services in the Council, in consultation with providers of education and support, the families and other stakeholders. The range of needs covered includes autism, learning disabilities, mental health and physical disabilities, especially whenever any of these combine in complex disabilities.
- 1.1.2 In particular it focuses upon the project with the National Development Team for Inclusion (NDTI) over the last 4 months to analyse the needs, options and plans for commissioning better services, and then the next steps in implementing their recommendations (the summary of their report is attached in Appendix 1). There was extensive consultation and involvement in this project with stakeholders, including carers, the Learning Disability Partnership Board and others.
- 1.1.3 The Health and Wellbeing Board has responsibility to promote the integration of health and social care and hence is asked to comment on and endorse the approach set out in this report. The project was commissioned jointly and the NDTI report strongly recommends the combined use of resources and practice to meet the increasing needs of young people with this range of disabilities. The Health and Wellbeing Board's comments will inform detailed proposals to go to the Council's Cabinet and PCT Executive in the autumn 2011.

2. RECOMMENDATIONS:

- 2.1.1 To support the recommendations from National Development Team for Inclusion to the NHS and the Council commissioners of health and social care
- 2.1.2 To endorse the project to produce specific outline business cases for investment and improvement to children and adult services for people with autism, learning and complex disabilities with health and social needs

What will be different for residents as a result of this decision?

Children and young people with disabilities will have long term care planning that improves outcomes, and the opportunities locally within their families and communities they need. They and their families will be better able to have choice and control in meeting health, housing, education, employment and care needs.

3. SUPPORTING INFORMATION

3.1 Background:

- 3.1 The concerns about increases to the costs and poor outcomes of out of area placements for education and care and for those young people with disabilities changing to adulthood, led to the formation of the Transition Working Group. Having scoped the numbers of young people with complex needs at risk of or in out of area placements (28 young people over the next 5 years), a project was agreed to develop commissioning plans short and medium term on a comprehensive basis. The annual cost of additional care costs at the age of 18 years transition to adults in the Council has been at least £400k for the last 3 years and is rising, alongside similar cost increases to the NHS Continuing Healthcare. The National Development Team for Inclusion was commissioned February – May 2011 to lead the project and the appendix 1 sets out the summary of their findings and recommendations.
- 3.2. The NDTI findings are that improvements can be made if there are long term individualised plans made with young people from an earlier age than present (i.e. 13 rather 17 years old). Also better coordination and combination of services across the sectors of education, health and social care, housing and employment will both improve outcomes and reduce long term costs, with the adoption of best practice.
- 3.3. There is now a high level of interest from practitioners, agencies and partners in working together on improvements as recommended, which gives impetus to the Action Plan being formulated. A new Transitions Steering Group will build on the work developed during the commissioning project and programme manage the different strands of activity envisaged. These will cover the four key areas: healthcare; social care and lifestyle; accommodation; and education, training and employment. The aim will be to start at school year 9 (13 years) and above in working with young people and their families to develop long term plans that can improve their opportunities in ways that focuses on them as individuals (i.e. person centred).
- 3.4. The national policy supports the approach being developed in RBWM as set out in the commissioning recommendations. The national autism strategy (2010) is important given the anticipated larger numbers with that disability coming through from primary school ages locally. The Valuing People Now policies for people with learning disabilities over the last 10 year support the My Care My Choice programme of personalisation of care and support underway in adults and now being adopted in children services. The Special Educational Needs Green Paper (2011) supports the person centred approach to supporting children, and young people with long term support that improves opportunities for local, family and community based solutions to their health, education and support in maximising their potential.

- 3.5. The regional aspects of specialist provision for young people will also be taken forward through joint initiatives underway in East Berkshire with Slough, and Bracknell Forest, and with the Primary Care Trust. The shortfall in local specialist provision is one factor that contributes to out of area placements for all these partners.
- 3.6. The translation of these commissioning recommendations into practical, costed proposals is a key objective for the new Transition Steering Group and will lead to papers with such proposals being submitted to the RBWM Cabinet and other key decision makers in the autumn with appropriate consultation to follow as necessary. The Health and Well Board's endorsement will help inform those proposals. Progress in implementing the recommendations will be reported to the respective Partnership Boards that will link to the Health and Wellbeing Board.

4. OPTIONS AVAILABLE AND RISK ASSESSMENT

4.1 4. Options

	Option	Comments	Financial Implications
1.	No endorsement of the NDTI recommendations	The previous ad hoc arrangements have led to high levels of out of area health and social care placements	Average of £500k annual costs of placements transferred from Children to Adult Services and similar for the NHS.
2.	Implement the NDTI recommendations	See the Executive summary in Appendix 1 for the detail	Long term reduced costs from better local outcomes for those with disabilities
3.	Pilot the "demonstration projects" in Children and Adult Services to help those in out of area placements return to local and family settings	Both pilots can be carried out within existing staff and other resources in 2011/12	No additional costs, and potential long term reductions on current and future costs
4.	Develop a full action plan to implement the recommendations in the proposed Commissioning Plan	The draft Action Plan is being developed that covers short term implementation of change, and the design of longer term proposals	To work within existing budgets but with improved coordination aim to reduce costs, with Project Management support
5.	Establish the Transitions Steering Group as recommended with accountability through the Health and Social Care Executive to the Health and Wellbeing Board, as for RBWM as a major project	Build on the existing Transition Working Group, with a wider range of stakeholders represented	Development Fund (RBWM) bid to include project management capacity in first 6 months to support such a group coordinate the Action Plan.

4.2 Risk assessment

- 4.2.1 The risk of the current ad hoc approach to multi disciplinary and multi agency responses to increasing needs for the range of disabilities is one of inconsistent and high costs of outcomes that the most complex and dependent young people experience. The improvements recommended are both short-term and others longer term. The former are being developed in pilots immediately, and the latter will involve proposals in the autumn to the RBWM Cabinet and PCT Executive.
- 4.2.2 The demonstration pilots will be focused on a small number of users and carers in both children and adults, with cooperation agreed with users and carers from the outset. Multi disciplinary approaches to assessing and supporting alternative provision will be deployed to ensure the holistic outcomes recommended are achieved. The risks should be low and changes made by agreement.
- 4.2.3 The Action Plan is based upon local agencies agreeing to cooperate across education, health and social care to work towards improved outcomes. Where detailed investment decisions are required or consultation necessary, these will put in a Cabinet paper in the autumn 2011.
- 4.2.4 The Transitions Steering Group will be more transparent, and accountable for commissioning improvements through the new arrangements proposed thereby reducing the risk of uncoordinated responses to need and pressures across agencies. The wider regional aspects of commissioning with NHS or other partners will be the subject of a separate workstream under the East Berkshire Strategic Commissioning Group of Directors.

5. CONSULTATIONS CARRIED OUT

- 5.1.1 The officers from RBWM, PCT, NHS and education partners, the Learning Disability Partnership Board members, carers, and other stakeholders including service providers took part in a series of workshops with NDTI in the development of the research, options and recommendations.
- 5.1.2 There will be thorough consultations with the Children Partnership board, the Learning Disability Partnership board, and other stakeholders on the implementation of these proposals. It is suggested that the outcomes are reported to the Health and Wellbeing Board in early 2012.
- 5.1.3 An equalities impact assessment has been started and will be in place before the Board meets on 15 July 2011. This will focus on improving the equality of opportunity for children and adults with disabilities.

6. COMMENTS FROM THE OVERVIEW AND SCRUTINY PANEL

- 6.1.1 A Cabinet report to consider detailed proposals will be scheduled for October 2011 and the Panel will be briefed accordingly to comment on these and related issues.

7. IMPLICATIONS

7.1.1 The following implications have been addressed where indicated below.

Financial	Legal	Human Rights Act	Planning	Sustainable Development	Diversity & Equality
x	x	x			x

Background Papers:

7.1.2 Appendix 1: The Executive Summary of “the Commissioning Recommendations that build capacity in the RBWM” from the National Development Team for Inclusion (NDTI)

APPENDIX 1

National Development team for Inclusion

**Commissioning Recommendations that build capacity in the
Royal Borough of Windsor and Maidenhead**

May 2011



Executive Summary

Introduction

This report presents commissioning and development recommendations designed to improve local opportunities, services and supports for young people with Special Educational Needs (SEN) in RBWM as they become young adults. The 'transition' to adulthood encompasses the period when most young people are developing their independence - leaving school, possibly going to college, starting work, forming relationships and maybe leaving home. It is the time when young people prepare to start their adult lives. It is generally accepted that the transition period starts from Year 8 of a young person's schooling and ends by age 25, when most will have completed any further education.

Good transition support focuses on identifying and working to achieve the personal *outcomes* that a young person wants, with the involvement of their family and/or people who know them well. The principles of equal opportunity, equal citizenship and social inclusion are synonymous with good transition outcomes for young people with Special Educational Needs. 'Good transition' is about a young person's whole life – how they will live, learn, work, see friends, have fun, stay healthy, get around, meet people and build relationships, and more. Getting the opportunities and support right so that young people achieve and sustain good outcomes in all of those areas is the commissioning challenge.

The need for a plan

The impetus to develop a specific 'transition' commissioning plan has come from a desire to build local capacity so that young people can be supported within RBWM who would otherwise go to high-cost out borough placements. 18.7% of school age children with SEN from RBWM are attending special schools *outside* of the borough, at least 11.9% at *independent or non-maintained* special schools. As well as the impact on young people of moving from their home area, there is significant investment going outside of RBWM rather than being used to build capacity and skills within.

The majority of young people are placed in schools outside of RBWM *before* Yr 9 i.e. before the statutory transition planning period. Most are placed because RBWM schools cannot meet their specific educational needs or find

it hard to address behavioural challenges presented. 21 young people are currently in combined education with care placements. The pattern is that, at 18 / 19, most move on to residential care settings away from their local area, with significant resource implications for the Council's Adult Services and the Primary Care Trust (NHS Berkshire East). The majority do not move into employment.

28 children per 10,000 in RBWM have a Statement and attend independent or non-maintained special schools compared to a national average of 10 per 10,000 in 2009. For 2010/11 the Council and the PCT projected a combined spend of more than £9 million pounds on supporting children and young people in education placements.

Young people with SEN in RBWM

- At May 2011 there were **674** school age children and young people from RBWM with a statement of Special Educational Needs. 2.87% of school age children have a Statement of SEN, compared to 2.7% nationally.
- Figures demonstrate a significant increase in children with medical needs and children with Profound and Multiple Learning Disabilities in school years 1 - 7.
- The majority of the young people in 'education with care' placements present behaviours that are extremely challenging: school and family pressures and safety issues were major factors in reason for placement.
- 27.9% of Statemented children in RBWM have Autistic Spectrum Disorder as their primary need compared to approximately 20% in a local comparator borough and a national average of 18.8% in 2010
- The ethnicity of young people with Statements of Special Educational Need in RBWM is becoming more diverse. There is particular growth in young people of Pakistani background: the majority are likely to come from Muslim families.
- The YPLA is funding ten young people from RBWM to attend out of area Colleges at a cost of c £696,000. Each has very individual and unique needs, with no clear pattern. In 2010 six young people moved directly from out of area schools to out of area College placements.
- Eleven young people are leaving out of area Colleges in June 2011, nine going on to local Colleges, a pattern described as a 'college

roundabout'. There are concerns that some placements may break down because of lack of individualised specialist support for people with high support needs, sensory needs, autism and challenging behaviours, particularly around communication, and lack of forward planning for accommodation and support.

- Most young people attending Manor Green Special School are reported to move on to College placements. Those who don't are mainly young people with higher support needs. There is also a concern that some young people from BME communities may be leaving school and simply staying at home because their families are less aware of the options available.
- Numbers of young people referred for support via Adult Social Care have increased over the past three years. In the past two years there have been approximately 45 referrals to the Community Team for People with Learning Disabilities and specialist ASD social workers and approximately 5 referrals to the Physical Disability Service.
- The Primary Care Trust is currently funding support / services for 23 young people aged 0 – 25 through Continuing Healthcare provisions with a forecast spend of £1.516 million. Of the six young people with significant healthcare needs over the age of 18, all but one has learning disabilities
- Ways Into Work, the RBWM supported employment service, has seen a significant increase in the number of young people aged 18-25 that it supports, almost doubling in a year from 36 during 2009/10 to 67 young people now.
- From January 2008 to July 2011, RBWM day services for adults with learning disabilities have received 10 referrals for young people aged 18 – 25. Four were leaving Manor Green Special School, 4 were College leavers and two had moved into the area.

Current opportunities, services and support

There has been a great deal of very good work going on in RBWM to 'improve transitions' for young people with SEN. It is important to build on that good work. It is generally agreed that there is still room for improvement.

The introduction of Personal Budgets in Adult Social Care is in its early days in RBWM but young people who are eligible are allocated a Budget and helped to develop a support plan detailing how they will use the money to

meet their needs. Children's services in RBWM are not yet piloting Personal Budgets but there is interest and enthusiasm for doing so.

Significant improvements are needed to the statutory transition planning process across all schools in RBWM. In particular –

- Making the transition planning *process* more person-centred and outcome focused
- Raising aspirations, understanding and belief about positive lives for young people with Special Educational Needs.
- Agreeing pathways to employment, housing, learning, healthcare, social inclusion, and to funded support – and which agencies will do what, including for Looked After young people and young people placed outside of RBWM.
- Linking transition planning to Personal Budgets at an *earlier* age so that young people and their families have more control and can take the lead.
- Building enablement and preparation for independence more clearly into the transition process, linked to an eligibility check for Adult Social Care and Continuing healthcare funding at age 16.
- Helping professionals to work in a more coordinated and integrated way to avoid young people and their families having to 'tell the story over and over', and to make more efficient use of professional capacity across agencies.

Access to supported accommodation that is uniquely right for each individual young person is a significant issue. Availability of land for new build housing is limited, and developments are largely blocks of 8 - 10 flats grouped together in urban areas. RBWM has significant provision of supported accommodation for adults with learning disabilities within the borough but much of it is not currently suitable for the young adults who need it. The learning disability service supports 249 people to live with family carers or have their own tenancy or own their property (70.5%). 104 people (29.5%) live in residential care, of which 45 live outside of RBWM. The majority of these residential placements supporting people with challenging behaviours and autism. This reflects the lack of local specialist provision to meet the needs of people who present with a complexity of need.

The single provider of 'supported employment' in the borough, Ways Into Work, is highly regarded and respected, but the service does not work with young people under the age of 18. Work experience placements for young

people with SEN at school are very limited in their range and significant improvements are needed. Disability Employment Advisers at the three JobCentrePlus offices in RBWM refer people on to Ways Into Work if they are unable to meet their needs. Local Colleges have limited staff capacity to support people into employment.

East Berkshire College and Berkshire College of Agriculture (BCA) both offer discrete courses for people with SEN as well as mainstream courses. East Berkshire College has developed particular provision for people with Autistic Spectrum Disorder and BCA is developing provision for students with high support needs. There are a number of significant issues for potential students with SEN who are considering either College – built environment issues, competition for places, limited support outside of lessons, not admitting people who present challenging behaviours, no organised support beyond course hours, issues re travel, and lack of supported student accommodation.

38 children and young people in RBWM receive a Direct Payment from the Council to purchase their own support. Finding Personal Assistants who are trained in lifting and handling / physical disability is difficult for families, and existing agencies struggle to meet demand for home-based support during peak morning and evening hours.

Availability of *skilled* support for people who present the most challenging behaviours and/or Autistic Spectrum Disorders is problematic. There are issues around accessing appropriately skilled support as *well as* accommodation at relatively short notice or at a point of crisis; the need to approve providers whilst in the process of trying to arrange a support package for a person; high cost of support due to a competitive local employment market; and no services to support young people who aren't eligible for funded support via Adult Social Care, but who *do* need low level support (e.g. after College hours or in holidays).

The Council, Berkshire East Community Healthcare Trust and Berkshire Healthcare NHS Foundation Trust employ a range of professionals who advise and support families, schools and other providers during a young person's transition years. The professionals are based in a number of separate teams across different agencies and departments, either focusing on children or adults. It is a complex network, and children's services are currently considering how to achieve more integrated working and wraparound child and family-support – which is to be welcomed. Continued separation of the SEN and LDD services may not be helpful in achieving that aim.

Once a young person leaves school and/or reaches 18 the professional support available decreases. This is a particular issue for young people who

present challenging behaviours and / or have an Autistic Spectrum Disorder, young people with communication issues, and young people with complex health issues.

For families, RBWM has developed a range of services that enable children and young people to experience ordinary fun activities away from home. A new residential respite unit in the grounds of Manor Green Special School in Maidenhead can accommodate 24 young people, in six connecting units, one of which is designated and equipped for young people with complex healthcare needs. For young adults aged 18+ and their families the range of non-residential short break provision is very limited, with no development capacity to grow provision. With the profile of young people coming through transition in the future there will be continued and increasing need for provision that is equipped and skilled in supporting people with complex physical and healthcare needs, gender specific, skilled in supporting people who present challenges and/or have Autistic Spectrum Disorders, and available overnight as well as in the evenings, during weekends, and after College hours. RBWM's four bed residential respite unit for adults with learning disabilities is a limited resource and investigation and consultation is needed to ensure future needs can be adequately met.

There is no advocacy service available for young people across the 14 – 25 age range, though a service for adults with learning disabilities is available from the age of 18. The Mental Capacity Act applies from age 16 and greater clarity is needed about how provisions such as Best Interest assessments can be met during transition planning. RBWM has not invested in structured approaches to develop family leadership during transition. When linked to Personal Budgets, and with support, family leadership has been shown to achieve excellent person-centred transition outcomes for young people.

Achieving change

The report considers the challenge of making plans happen for young people 'in transition' when opportunities and supports are the responsibility of numerous different agencies and departments. Strategic development and funding partnerships are essential, as is a managed approach over a number of years. We suggest commissioning *priorities* and an action plan designed to create:

- *a managed network* of opportunities, supports and services in RBWM for young people with SEN as they reach adulthood
- *strategic partnerships* that make best use of local resources to achieve what's needed.

There are substantial gaps in opportunities, services and supports for young people with Special Educational Needs in RBWM. We indicate a number of developments that would help to address those gaps, and some services and supports that should be specifically commissioned. Some are more urgent than others, and we recommend that the transition commissioning plan takes a phased approach, identifying action over a two year period. It is an ambitious but necessary agenda that will require an investment of both time and funding.

To achieve change three particular issues will need to be addressed -

- The strategic group driving forward transition developments and commissioning does not have strategic involvement from across the range of agencies with a role to play in transition. It needs to be broadened and formalised into a strategic Transition Partnership
- There is limited development capacity across agencies to lead and work on the changes needed. This will need to be enhanced.
- Young people placed out borough in expensive placements have unique and challenging individual needs. Meeting those needs within borough will require a significant investment of resources and time *across agencies* in order to achieve longer-term gains.

There are knowledgeable and committed professionals across RBWM with the desire and will to change things to achieve better outcomes for children and young people. There is a level of frustration across staff, services and agencies that change is not happening. There is a sense of vision, and additional development capacity is required for this vision to become a reality.

Development and Commissioning priorities (in summary):

Achieving positive outcomes – making change happen

In Year 1	In Year 2
Re-launch the Council's Transition Strategy Group as a Transition Partnership, with wider membership at strategic level.	Build on the Partnership
Set up time-limited work groups, with a specific remit to develop resourced <i>Partnership</i> plans to achieve commissioning recommendations. Give priority to groups focused on a) the transition planning process, b) employment support, c) supported accommodation, d) extending FE opportunities.	Implement the Partnership plans
Identify a Transition Programme Manager who is knowledgeable about transition issues and skilled in supporting development groups.	Continue Programme Management
Commission a Transition Leadership course for families and young people Encourage and support parental / family involvement in developing the commissioning plans further	Roll out to more families and young people
Clarify the data that the Council needs for planning purposes and discuss development of a predictive planning model for transitions with the Berkshire sub-regional group (SRG).	
Free up land and revenue to help make the recommendations in this report happen through a review of existing accommodation for adults with learning disabilities.	Implement the review findings

Improving transition planning

In Year 1	In Year 2
Introduce person-centred transition planning into Manor Green Special school and one mainstream school.	Roll out person-centred transition planning across more RBWM schools.
Build on the Getting A Life Pathways to clarify who will do what and when in RBWM, including for Looked After Children and young people placed in independent schools or out of area placements.	Implement the pathways
Set up a demonstration project focusing on a small number of young people in high cost out of area placements – demonstrating transition to person-centred <i>local</i> solutions.	Evaluate and implement lessons
Introduce Personal Budgets for young people in transition as well as an indicative eligibility check for Adult Social care & Continuing healthcare funding at age 16, with indicative Budget. Link to a two year enablement period before final Budget agreed at 18.	
Integrate Continuing healthcare funding into the Personal Budget process.	
Commission a <i>virtual</i> transition service for disabled young people attending Manor Green School. Evaluate effectiveness and outcomes.	

Supporting schools and families to prevent *out borough placements* before the transition period

In Year 1	In Year 2
Develop a Family Centre and trans-disciplinary early intervention and prevention team linked to Manor Green	

School.	
Commission training, linked to a comprehensive training strategy focused on preventing out borough placements and developing staff skills within RBWM.	
Commission family-style boarding provision for school children, commissioning support/care provision through a competitive process, alongside positive action to recruit short-term shared care (family-based) options.	
<i>Significantly</i> reduce the capacity of the residential respite service at Manor Green school this year and develop a plan, with families, to increase <i>non-residential</i> respite options for young people with very complex needs. Commission support/care provision for the above through a competitive process	Reduce the residential respite provision at Manor Green further
Continue to develop home-based, social activity and family-based short breaks for families to choose from.	
Commission additional communication expertise (Speech & Language Therapy) to support schools and local Colleges to develop inclusive communication environments.	
Consider integrating the Council's SEN and LDD services to achieve a more unified approach.	

Individualised approaches and skilled support

In Year 1	In Year 2
Commission support on an individualised basis for people presenting challenging	

<p>behaviours, ASD and complex healthcare needs.</p> <p>To enable this, identify a small number of RBWMs community support and/or education providers who have proven skills in person-centred, individualised support to people presenting challenging behaviours, ASD and complex healthcare needs – testing indicative quality and costs before entering into preferred provider development partnerships with them.</p>	
<p>Develop an individualised commissioning process for social workers / care managers, supported by training</p>	
<p>Build incentives into the commissioning process (e.g. profit sharing when targeted reductions in support are achieved over time), encouraging use of Assistive Technology and innovative approaches</p>	
<p>Produce a specification for Allenby Rd respite unit that addresses the changing needs and ethnicity profile of young people in transition, and includes development of community-based breaks. Commission the service through a competitive process <i>or</i> seek an independent provider to develop the provision.</p>	

Extending supported employment provision

In Year 1	In Year 2
<p>Commission Ways Into Work to provide a work experience and supported employment service to young people at Manor Green School.</p>	<p>Extend Ways Into Work provision to young people in resourced units across RBWMs schools.</p>

Ensure existing community support providers pursue employment outcomes with young people, through contract modifications	Automatically build into new contracts
	Identify and progress social enterprise opportunities that could provide employment for some young people
	With the YPLA, commission the two local Colleges to develop a tailored <i>action learning course</i> on self-employment and business i.e. learning through doing
Ensure Ways Into Work has staff with the requisite skills to support young people with ASD	Continue to build staff skills

Developing the local FE offer

In Year 1	In Year 2
Build communication support for students into College core funding for approval by the YPLA.	
Develop student buddy schemes at BCA and East Berks College.	
	Develop student accommodation near the Colleges and commission a provider to directly support the students, develop their independent living skills, and work alongside the College to help them progress into work and longer-term accommodation.
	Commission an accredited programme of community-based, individualised learning.

Supported accommodation

In Year 1	In Year 2
Work with a Registered Social Landlord to identify accommodation for the development of a Living Support Network for young people with ASD and low level support needs. Commission support separately.	
Bring negotiations to develop a Shared Lives Scheme in RBWM to a positive conclusion, and then consider commissioning the service to provide family based short breaks for both children and adults.	
	Explore the viability of entering into a formal agreement with a private landlord for individual tenancies.
Commission workshops for families on how to get housing for their young people, including Shared Ownership	
Develop a specific accommodation strategy for adults with social care needs that takes into account the requirements of young people in transition. Review existing provision for adults with learning disabilities and resettle people or reconfigure the accommodation so that people have their own tenancies, freeing up both land and revenue to help make the recommendations here happen.	