

**Turning Point's Consultation Response
August 2004**

Introduction

1. Turning Point welcomes the opportunity to comment on the Strategy Unit's Analytical Report; Improving the Life Chances of Disabled People. Turning Point is the UK's largest social care charity working with individuals and their communities in the areas of mental health, substance misuse and learning disability. We have over 200 services in England and Wales, spanning day support, outreach, residential, nursing and 24-hour crisis provision. We have particular expertise in working with people who have complex needs and are facing multiple social challenges.
2. Turning Point has already met with officials to discuss the Life Chances Project and the Turning Point/ippr report *Meeting Complex Needs, The Future of Social Care*. The Turning Point/ippr report articulates how health and social services are not meeting the breadth and depth of people's needs and makes recommendations for policy development, commission and the delivery of services in relation to complex needs which will impact on the Life Chances report. It makes the case for a standard form of contract, contracts that last for longer periods than currently to allow for services to bed down, and for the voluntary sector to be able to raise sums for capital development. It also calls for a new model of service delivery- Connected Care Centres for people with complex needs. These centres would be situated in the most deprived communities and would provide a link for communities into mainstream services.

General

3. We welcome the attention the Government is giving to improving the life chances of people with a disability, particularly in light of the Social Exclusion Unit Report, Mental Health and Social Exclusion. As the interim report acknowledges, it is vital that the Government recognises the heterogeneity of disability. Although there are many issues and barriers which people with different disabilities have in common, the report needs to recognise that variety and flexibility are key. The emphasis must be on people as individuals and finding holistic solutions to their particular support needs and dismantling the particular barriers they face. Particular consideration should be given to people whose disabilities are 'hidden' such as epilepsy or dyslexia. Furthermore stigma and other reasons may mean that some people find it difficult to acknowledge a disability or do not perceive themselves to be disabled, but nonetheless may benefit from support, for example some people with mental health conditions.
4. The report also needs to recognise that there are some disabled people who may be more likely to experience poor life chances or discrimination or whose current situation makes them most vulnerable. This is likely to include people from black and ethnic minority groups, people with multiple needs/conditions (such as mental health and substance misuse problems) people with a learning disability who remain in long stay hospital or other NHS facilities,

people with a learning disability who are parents, people with high individual support needs and people with little or no formal communication and people living in more deprived areas.

5. The Strategy Unit's work also needs to link into other initiatives include the work the Department of Health and the Social Care Institute for Excellence is undertaking in relation to "A New Vision for Social Care".
6. In relation to the drafting of the report, we found the report difficult to digest. We think the layout was unhelpful as it was confusing to follow and made it very difficult to find key points and questions within the text and diagrams. The length was also a disadvantage.

Principles for the mainstreaming the needs of people with a disability

7. Turning Point welcomes the principles for mainstreaming the needs of people with a disability set out in the report. We agree that it is important that responses to the needs of each person must be based on them as individuals and need to be person centred and timely. This requires a holistic approach to service design and delivery and should cover all aspects of an individual's life.
8. Choice between services should be available but the Government must make sure that minimum standards are set and achieved. The minimum standard must also be set at a high level to ensure that all interventions and support disabled people receive are of good quality.
9. Enabling and empowering people to make choices is critical. The Mental Capacity Bill is central to this. So too is advocacy. Advocacy is essential to enabling people who may otherwise find it hard to make decisions, or to speak up for themselves to be empowered. If the Government is serious about user involvement and involving people as equal partners, both in individual decisions about their own support, but also in providing direction and influencing development of future service provision, the provision of independent advocacy must be a priority. Without it, people who find it the hardest to have their voice heard will continue to be missed out and left behind.
10. That services and Government need to be more accountable to people with a disability is critical. Complaints procedures are often difficult to understand and people with a learning disability report that their complaints are sometimes ignored. In addition, there are often long delays in giving feedback or taking action as a result of a complaint services like ICAS and PALS will be important in supporting people with a disability to complain and hold services to account.

Early Years

11. It is important that the proposals in the report reflect the development of Children Trusts and the National Service Framework for Children. It also needs to reflect the needs of families as well as individual children and their parents.

Keyworking

12. It is useful to consider good practice in the adult field and look at how principles/models of good practice can be applied to children. For example, having a “Named Person” (or key worker) responsible for co-ordinating or negotiating through services was a commitment in Valuing People. Where this has been implemented successfully, it may provide good practice for children. Key working is also a feature of many substance misuse and mental health services.

Multi-agency working

13. Multi-agency working requires people to be confident about sharing budgets and information. People may be reluctant to work across health and social care because they are concerned that they may lose their budget. This may also be true within organisations where budgets are split. Enabling people to take risks and to share budgets more easily would help multi-agency working. There should be greater priority given to locally based multi-disciplinary training, exchanges of information between specialist and general agencies and the promotion of secondments between staff and to specialist posts. This will help to promote closer working between different agencies and raise awareness of local issues.
14. Partnerships can also be improved by: overlapping board memberships, joint delivery strategies, co-location of service provision, and staff exchanges. Each agency should have a named individual responsible for maintaining partnership arrangements and local leaders should be seen to actively promote the partnerships. Staff should have accountability to partnerships built into their job description.

Transition

15. The transition between children and adult’s services can be very stressful time for many young people and may leave them and their families vulnerable to exclusion and isolation from service provision. The experience of young people is that young people services tend to be better able to meet a range of needs and support the individual holistically. This is often not the case in adult services which can be poorly equipped to meet additional social care requirements and are not designed for young people and in some cases, equivalent services are simply not available. In addition, the transfer from young people services to adult services can mean a change in location of the service. This can cause problems as services are not provided on an outreach basis in the young person’s home, or they are further away from where they live or may be in inappropriate locations
16. We think the analytical report should be stronger in its description of the barriers young people face in moving into adult services (see p19 of the analytical report). Eg, Although many disabled young people and their families experience multiple assessments, a significant number do not receive the assessments or service at all. The problems faced by young people trying to transfer from Child and Adolescent Mental Health Teams to adult services and the shortage of services are widely known (*Provision of NHS Mental Health Services*, Health Committee, July 2000). From a young person’s viewpoint they lose their right to services that were provided as a

key anchor in them combating the effects of disadvantage, likened by some to 'falling off a cliff'. This can also be the experience of young people with a learning disability.

17. There is though a debate about whether it is appropriate to develop separate provision for young people. Young people specific provision risks creating another boundary and may discourage adult services from becoming more responsive. Our experience suggests that both approaches are needed: at times a specialist young people's service will be required, but it is also vital that 'adult' mainstream services are flexible and focused on the needs of young people. It is also possible to provide youth oriented services within adult provision such as offering clinics/appointments at certain times/days. Improved skills sharing between young people and adult service provision could encourage more responsive service provision.
18. Eligibility criteria of different services should also be examined. The eligibility criteria for many young people's services may be broader than their adult equivalent which can make it difficult when the young person reaches the set age when they should transfer to adult services as they will no longer meet the eligibility criteria. Choice can also be limited due to a lack of alternative service provision in many areas. This means that frequently there is no choice for young people of how they are supported.
19. In addition, the needs of families and carers should be taken into account at all stages. Whilst most young people's service providers now include parents and carers in care planning, adult services often neglect their needs and the fact that these may alter with any changes in service provision.
20. It is also important to recognise that people may experience more than one "transition". There may be a transition when a child leaves school to go to college, and then from college to adult services and employment, or when someone moves out from their family home or to a new area. Whenever there is a major change in how services are provided to the individual, or if something changes in their life, this requires a transition and they will need extra support to make sure this happens as smoothly as possible.
21. We consider that the following would make transitions easier for young people with a disability and their families:
 - Services should consider ensuring protective factors are in place to improve the transitional process. This may include transitional keyworkers, seconding staff between children and adult services, ensuring additional support networks are strengthened (ie families, carers and friends are supported) and the transitional process is well planned, timely and gradual.
 - Communication systems need to be improved and a greater sharing of practice which would enable services to understand how working practices vary and how this may impact upon the young person and their family. Making one person responsible for co-ordinating each young person's transition plan may ensure there is a single point of

contact for individuals. Good communication would also support multi-agency working.

- Periods of transition should be planned around a flexible timescale to ensure individual needs can be taken into account. Some young people will engage quickly with adult provision with others requiring a longer “cross over” period and more ongoing support.
- An assessment of the needs of the individual through the transitional period should be undertaken and this should include the individual, parents and services to ensure all views are taken into account. It should not be assumed that the needs of the young person will remain the same as they move into adulthood. Early information about what transition means from the family’s point of view should also be provided.
- Making sure children and young people who are placed away from home are given extra support and focus at transition stages. Specific services may need to be developed and designed which means the lead in time for arranging services and consulting with them and their families may be longer.
- Making sure that further and higher education and employment opportunities are presented as realistic options for children with a disability. Supported employment, volunteering and access programmes to training would enable young people to gain skills and experience suited to their needs and abilities. Specific programmes with high levels of flexibility can encourage opportunities for those not able to undertake paid work.

22. Under “If we get it right” section in the analytical report, the following additional benefits should be noted: continued engagement with services resulting in better long term outcomes including good social life and skills, lack of isolation, reduced vulnerability to other issues such as substance misuse, criminal behaviour, poverty etc.

Preparation and Prevention

23. Preventative strategies can have negative connotations for people with a learning disability as this can imply questions about the value society places on people with disabilities and their ability to contribute to society. The focus should therefore be on ensuring that people with life long disabilities are enabled to have the same opportunities as the non-disabled population. This may well include strategies to manage and prevent deterioration of their disability. It should include access to specialist services like mental health care, occupational therapy, physiotherapy, speech and language therapy and dieticians.

24. People with a learning disability can find it hard to access these services. This may be because services are simply not available, or it may be because referral procedures and eligibility criteria exclude people from services. Not

receiving specialist services can mean that opportunities to make positive changes are missed and existing problems remain or are compounded. Shortages in these areas need to be addressed and referral criteria need to be used appropriately so people who need the service receive it.

25. The impetus to mainstream the provision of health for people with a learning disability from Valuing People and prior initiatives means that it is important the mainstream workers having training in learning disability issues. Healthcare professionals often report that they do not feel confident in dealing with people with a learning disability and that the lack skills. As well as training mainstream staff it is also important that there is access to specialists when necessary.
26. In relation to mental health problems, early intervention and limiting the impact of a disability through timely support is important. For example, the Sainsbury Centre for Mental Health estimates that mental health problems costs the country over £77 billion a year through the costs of care, economic losses and premature death.¹ The Report of the Social Exclusion Unit on Mental Health and Social Exclusion, also outlines some of the costs to individuals and to society of mental health conditions and additional impacts such as increased GP contact, deterioration of physical health and housing instability.²
27. Many people with mental health problems find that if they are able to access help at all, the treatment options are limited or inappropriate. There are particular difficulties with accessing talking therapies and alternatives to medication.
28. In addition, it is vital that people with disabilities are able to access support when they need it. Many people experience long delays in obtaining suitable mobility aids or other equipment, which limits their quality of life and potential in employment.

Employment

29. As the report identifies, Turning Point's experience is that many people are excluded from improving trends such as rising income or improved educational attainments. It is important to note the recommendations of the National Employment Panel to strengthen incentives for Jobcentre Plus to support disadvantaged clients, tailor support to individual need, increase service user involvement and make better use of the experience in the voluntary sector.
30. An informal service by the Foundation for People with a Learning Disability found that only 7000 people with a learning disability in the UK are in employment. The vast majority of people with a learning disability are unemployed and the Government estimates that there is a shortfall of 20,000 full time day services places for people with a severe or profound learning

¹, The Economic and Social Costs of Mental Illness, Policy Paper 3 -The Sainsbury Centre for Mental Health, 2003

² Mental Health and Social Exclusion, SEU 2004 Annex B Social and Financial Costs

disability. This means there is a real lack of meaningful activities for people with a learning disability to do in the day.

31. Only 24% of people with long-term mental health problems are in work. They currently make up the largest group of those claiming Incapacity Benefit. (NB the reference 'to large numbers of stock' on p19 of the analytical report is inappropriate. Also, the first bullet point should refer to non-disabled **people**.)
32. Any review of day and employment services must take a balanced view between effective help to get jobs for those who are able to work, and continuing social and vocational opportunities for those who cannot. From Turning Point's experience it seems that some poor practice in the learning disability field also occurs in mental health, in that people are often involved in 'pretend' or simulated work in day centres, instead of real work in real workplaces. This devalues the person, gives them a negative experience of 'employment' and does not encourage them to work to their optimum. Sometimes people complete numerous training programmes, but do not progress any further and are caught in a revolving door situation. We hope that the modernised day service programme envisaged in both Valuing People and the Social Exclusion report will address these shortcomings and that modernisation is not seen simply as an opportunity to save money. With regard to mental health, the SEU Report considered various models and concluded that supported employment and Individual Placement and Support projects were significantly more effective.
33. We also think that the Progress2Work model in the substance misuse field might be a useful model for people with mental health problems. At present, Progress2Work is specifically designed to help people who have or have had a drug problem gain employment or training. This model has recently been extended to those who are homeless or have problems with alcohol or offending behaviour. One of its strengths is that the possibility of relapse is acknowledged and periods of relapse are allowed for on the programme.
34. The report suggests incentives for employers to move disabled people up the earnings ladder (p24). While career progression is undoubtedly a major issue, Turning Point has some concerns about incentives schemes in general.
35. On the whole, Turning Point takes the view that such schemes can be abused. They are not necessarily popular with employers, who are looking for positive attributes, rather than compensation for perceived lower performance. If there are incentives, these should not be linked to individuals, but to making buildings and resources more accessible, to benefit the current and future workforce. They could also relate to the provision of support for the disabled person which will support them in their job, but also lead to the development of natural support within the place of employment. For example, the supporter may educate co-employees on disability issues and ways to break down barriers at work so a natural support system for the individual (and future employees) develops.

36. Staff and service users at Turning Point cited the 'benefits trap' as one of the major and common barriers to employment. There are particular difficulties with the benefits themselves, but people are also put off by the system which appears to be complex, difficult to navigate and adversarial. These perceived difficulties are a major disincentive to taking up work. For example, the 16 hour rule makes an artificially large hurdle between working less than 16 hours and being able to work for more than 16 hours. Turning Point recommends scrapping the 16 hour rule and introducing a new in-work benefit which reduces as income increases. Alternatively, if the 16 hour rule is to be retained, there is still a need for greater support to enable more people to work for more than 4-5 hours under the Income Support disregard, but less than 16 hours. Another option is to increase the Income Support disregard to £40 to allow people to try working for longer.
37. Benefit rules, limits to the number of hours, low wages are all disincentives for people with a disability to work. There is no central government funding for supported employment and the different initiatives on employment are not always joined up. There also needs to be better links between social service departments, NHS Trusts, and employment services.
38. The work people with a learning disability or mental health problem do informally should also be properly recognised and paid for. Very often people with a learning disability become involved in local action or advocacy groups and through these are involved in consultations and Partnership Boards. Such work (as the equivalent of expert patients) should be properly recognised and, if appropriate, paid for.
39. The Strategy Unit Report should link in with the Department of Work and Pensions on initiatives such as Pathways to Work and Developing a Vocational Framework.

Transport

40. Access to public transport is a key factor in our quality of life. It determines whether we are able to hold down a job, see our friends and family, shop, or take part in leisure activities. For disabled people in particular, it represents the difference between social inclusion and exclusion within a community. The Learning Disability Taskforce annual report said that people with a learning disability find it hard to use transport because it is not accessible or it is too expensive. These problems are greatest for people living outside cities. In addition information like timetables and maps are often not easy to understand. Staff are not always helpful and don't understand the needs of people with disabilities. For example, some users of Turning Point's mental health services have had to explain and justify their disabled "status" when presenting their bus passes to bus drivers who have commented that they do not 'look disabled'. Or sometimes bus drivers refuse to alert people with a learning disability when it is their stop. These problems have been highlighted in the recent consultation of the Disability Discrimination Bill. This also demonstrated many people's disappointment about the Government's deadline of 2025 for when rail vehicles must be accessible.

Direct Payments

41. Direct payments enable people to take control of how support is provided to them. There is currently a low take of direct payments amongst people with a learning disability and people with mental health problems. This is despite the fact that it is now a requirement for local authorities to offer direct payments and new guidance by the Department of Health has been published about the provision of direct payments to people with a learning disability. This explains that the “willing” and “able” criteria to manage direct payments can be fulfilled even if people need significant support to help them manage the direct payment. The key issue is whether the individual can indicate what sort of support they want. The Government needs to make sure that such support is available to people who may not otherwise receive direct payments. It is also very important that such support is balanced and truly reflects the individual’s wishes. Circles of support, which may include family, friends, professionals and advocates will be important in ensuring the wide range of issues the individual needs to consider when managing their direct payment are considered so the direct payments are spent how they want.
42. Any increase in the number of people getting direct payments needs to be matched by availability of quality personal assistance and support. There is some concern that this is not current available and direct payments will not automatically lead to better quality service.
43. The Government also needs to consider how to provide the flexibility of direct payments for those people who are not able or willing to have a direct payment. For some people this may be trust fund or indirect payments which are managed by a circle of support.
44. There is also potential for considering how the different streams of cash funding that are provided by different statutory agencies - direct payments from social services, Independent Living Fund from the DWP and benefits such as Attendance Allowance from local DWP offices- link together. The number of different schemes can be confusing and may lead to limited awareness. This can mean people miss out on funding that they are eligible for and have a right to receive.

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