Progression – How to improve outcomes for people with learning disabilities and lower support costs (August 2012)

Introduction:

Well publicised increases in spending on learning disabilities have been accompanied by media stories that have highlighted some shocking cases of neglect, complacency and even abuse. People with learning disabilities also report frustration at limitations on their access to life opportunities such as work, a home of their own etc. It seems that support costs are escalating, but individual outcomes are not consistently getting better.

At Alder we could not accept this scenario nor could we accept that external and uncontrollable factors (e.g. demography) somehow make it inevitable. We, therefore, set out to find out what needs to be done to tackle poor outcomes and unnecessarily high support costs.

Alder's work with Authorities across Wales and in the Eastern Region of England has highlighted that it is possible to improve the outcomes for people with learning disabilities **and** lower the costs of supporting them **at the same time**.

Our starting assumptions:

Our previous work with people with learning disabilities persuaded us that we should work on the basis of three simple assumptions:

- 1st people with learning disabilities can continue to learn throughout their lives, albeit in different ways and at a different rate to people without learning disabilities,
- 2nd give a choice free from undue influence by others people with learning disabilities will choose independence over dependence more often than not, and
- 3rd our job (in social care and the NHS) is to enable people with learning disabilities "*Progress*" to the maximum degree of independence possible at each stage of their lives.

Our Approach:

Figure 1 shows that at each authority we worked with we explored:

- What authorities were trying to achieve and why (their strategies),
- National and locally held data to identify how strategies were being delivered and what their impact was, and
- Social work practice and the other support for people with learning disabilities (e.g. housing related, NHS) to assess whether they enable "*Progression*" to great independence, simply maintain the status quo or whether they, perversely, increased dependence levels.

Fig 1: Alder Approach
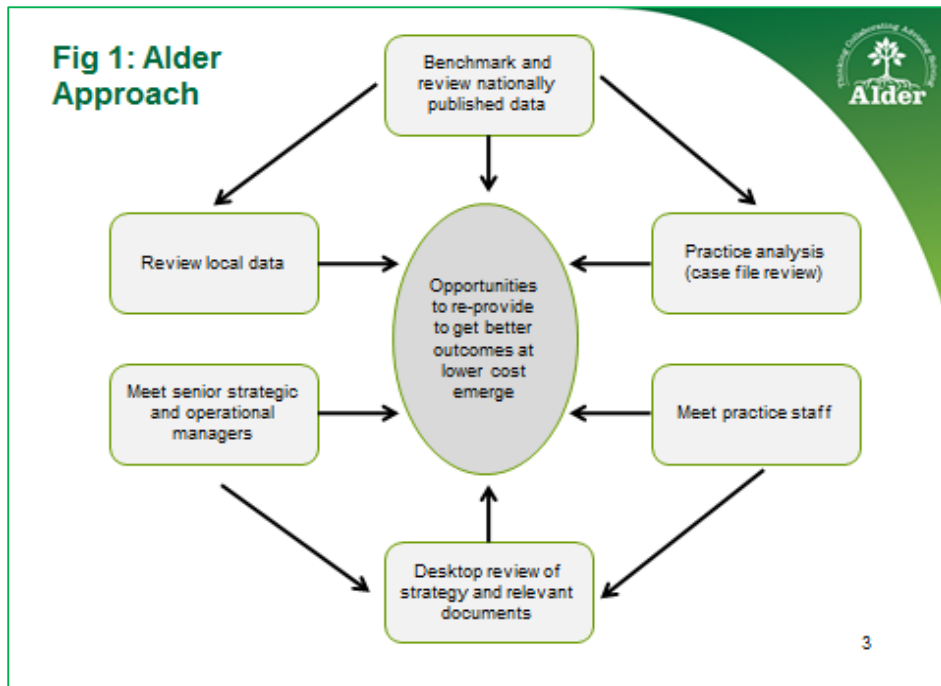
What we found:

Very large variations at the fourteen authorities we worked at in. For example the:

- Spending levels on learning disability support varied dramatically. For example:
    - Net spending per head of population varies from £114 to £203 p.h. aged 18-64.
    - The proportions of users with support packages costing of more than £1,500 p.w. varies 3 fold for care home residents e.g. from just 12% to 38% or residents and 20 fold for cases supported in the community e.g. from 0.5% of users to 10% of community based users.
- Support models used were quite different. For example:
    - The use of 24/7 models of support for people with learning disabilities varies from as little as 20% of users at one authority to as many as 45% of users at another one.
    - Some authorities use "shared lives" models extensively while others use it hardly at all. Some use it for a wide variety of interventions including respite, day support, emergency placements whereas others use it exclusively as an alternative to low cost residential placements.
- Approach to the assessment of need and support planning and its impact contrasted greatly. For example:
    - Attitudes to positive risk taking varied widely between authorities.
    - The emphasis on having S.M.A.R.T[1] objectives in support plans to guide interventions by support providers varied widely between authorities.
    - The majority of reviews result in no change e.g. at one authority 93% of reviews resulted in no change, whilst the proportion of support packages that reduce after a review vary from 0% at one authority to just 3% at the best performing authority.

Typically the savings identified at the 14 reviews were valued at between 5% and 10% of net expenditure on support for people with learning disabilities.

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[1] S= Specific, M= measurable, A= Agreed, R=Realistic and T= Time bound

Recommended Way Forward:

The "*wider (sometimes referred to as whole) system*" of care and support for people with learning disabilities needs to be focused on enabling each individual with learning disabilities to "progress" to higher levels of independence over time.

An individual's "*Progression*" should be at a rate that suits them and should be enabled in ways that the individual is comfortable with and take a proportionate approach to risk.

The main components of a care and support system that promotes and enables "*Progression*" are given below in figure 2.

Figure 2:

At the heart of implementing "*Progression*" are a:

- A culture across the wider system of care and support that emphasises outcomes,
- Processes that ensure pro-active work aimed at supporting progression does not get displaced by the inevitable demand led responsive and safeguarding work, and
- A structure that includes a "*Gateway Team*" that works with all new referrals to ensure their potential to "Progress" is properly understood and support plans are designed to deliver this potential. This team would also work with existing users/ patients working with the most potential to progress and with the desire to become more independent.

If you want more information about how to implement the "*Progression*" approach for supporting people with Learning disabilities better and at less cost please contact either:

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