

Workshop with Family Carers (Transition)

Challenging BEHAVIOUR foundation making a difference to the lives of people with severe learning disabilities

Early Intervention Project

Wednesday 29th January 2014

Outcomes:

- To understand what works and what doesn't work during transition from childhood to adulthood, for young people with learning disabilities whose behaviours challenge
- To develop some specific recommendations to enable the "Preparing for Adulthood" team develop a specific resource on supporting effective transition for this group of young people

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1. What works and what doesn't work

Attendees introduced themselves and spoke about their family members' experiences of transition including what worked well and what didn't work.

What doesn't work

- Attitudes of some professionals. One was quoted as saying "the trouble is, parents have high expectations"
- Hospital appointments- reasonable adjustments are not made, challenging behaviours increase.
- The lack of options, both for education and for wider support and care
- Lack of support for sleep issues
- Lack of speech therapy/communication development
- Exclusion from school for challenging behaviour caused by staff not being trained in PBS resulting in young people with more restricted lives (eg 3:1 support and regular use of restraint)
- Residential school a long way from home
- Being driven to crisis point by the transition process and presented with the view that having a family member sent far from home is the only real viable option.
- Sudden, unplanned changes in school, housing or support.
- Difficult to find well trained staff, experienced in supporting people with learning disabilities whose behaviours challenge.
- Restraint/arrest being handcuffed and thrown in a van with no understanding of what was happening
- Local authority cuts leading to reduction in short breaks and SLT in some areas

What works

- Attending college near home
- Advocacy both for young people and for families
- Professionals who listen, learn and help young people and their families to develop skills
- Parents having the option to chair meetings related to their children/young people
- Good information for young people and families
- Young people supported to socialise/meet others/develop friendships and interests
- CBF helpline support without having to live in a particular area
- Early diagnosis and support
- Early Speech and Language Therapy
- PECs/Total communication
- Health passports so information does not have to be repeated to all professionals.
- Living in own home, near family, with good support staff.
- Learning disability liaison nurses in hospital to ensure reasonable adjustments are made and treatments are co-ordinated. So for example, health MOTs could contain all check ups in one go, or while under anesthetic for an operation dental work could be performed too.
- Creative employment opportunities eq Manchester Met university, SHIEC project

Example of developing a creative housing solution, working with the Housing Association, for three
voung men to share a house.

2. Supporting young people with learning disabilities whose behaviours challenge to achieve the Preparing for Adulthood outcomes.

Workshop attendees split into two groups to consider each of the Preparing for Adulthood outcome areas and the specific support required by young people with learning disabilities whose behaviours challenge, to help them achieve those outcomes.

a. Good health

Key message: "Young people have the same rights to good health and good healthcare as everyone else but currently people with learning disabilities are all too often denied those rights".

Planning and prevention

- Understanding of the link between pain and challenging behaviour. Check physical health as a potential cause of challenging behaviour (eg teeth, ears, pain) See CBF information sheet.
- Ensure regular health/dental checks
- Listen to families and people who know the person well
- Ask the right questions, avoid "diagnostic overshadowing"
- o Good communication use the right communication method for the individual

Proper, individual, reasonable adjustments

- As far as possible make sure support comes from people who know or are familiar with the person
- Understand the individual needs of the person and provide reasonable adjustments that meet that need eg firt appointment of the day, early appointment before it gets busy, understand the impact of surroundings – lights, machinery etc
- Explore worst case scenario have a plan to minimise chances of it occurring and a plan for response if it does occur.

Mental health support

- Understanding of the link between mental health and challenging behaviours (see CBF information sheet on mental health problems.) Challenging behaviour is not a mental health problem, but people are at least as likely to suffer from mental health problems as the rest of the population and mental health problems need to be recognised and addressed appropriately.
- Support should be provided as for physical health (above)

b. Education and employment

Key message: People with learning disabilities add value to their communities and need the chance to learn and work within their local communities.

- The opportunity to attend school or college close to home
 - Behaviour support available within local schools, using PBS approaches (staff trained and specialist teams brought in as necessary)
 - Total communication used within school/college

> Lifelong learning to support skills development, including

- Communication
- Waiting
- Skills to promote independence
- Skills for enjoyment
- Skills for employment

Employment opportunities

- Time banking/voluntary work
- o Job carving different employment profiles for paid employment see SHIEC project
- Provide practical pathways to employment address benefits issues which act as disincentive
- People with learning disabilities as employers, contributing to the economy
 - Support for young people/their families to employ carers/support workers with direct payments/individual budgets
 - Support for family carers, recognising the contribution they make and the support they need

c. Housing/independent living

Key message: "Everyone can live in the community with the right support – we must find the right housing in the right place for the individual."

- "One stop shop" to help explore options/facilitate housing solutions
 - Renting, sub-letting, own home, support within the family home where appropriate how to do it? (See CBF info sheets "planning a house" and "8 ways to get a house")
 - Brokerage role with access to solicitor/vol orgs etc
 - LA support
- Packages of support to enable independent/community living
 - Care provider and housing should not come as a package, so if one breaks down the other can remain consistent
 - Advocacy to ensure private landlords or support agencies take responsibility when things go wrong (eg boiler breaks down...)
 - o Recognise that needs change and regularly review the situation
 - Add a "care" category to JC+ recruitment site
- > Specific focus on behavioural needs appropriate housing for the individual in the right place
 - Start with the "ideal" and then see how far you can make it possible
 - Housing designed to minimise challenging behaviour eg outdoor space, near family, minimal siren noise (whatever is appropriate for the individual)
 - o Consider compatibility issues in shared housing
 - o Proper planning, involving those who know the individual well
 - Consider sustainability and long term security
 - Get the basics right eg bath/shower arrangements
- ➤ Consider planned "transitional" housing for young people -2 or 3 person shared house for a few years while options explored, assessments take place, ideal solution is developed and finally appropriate long term housing found.

d. Friendship/community inclusion

Key message – "we should not just support young people to exist, we should support them to live. This means real choices, a "can-do" attitude and positive risk taking."

- > Use social media to advertise inclusive activities for children and young people
 - Facebook page to raise awareness of activities –national (CBF?) and local (inclusive activities as part of "local offer?") eg "relaxed" theatre performances, sporting activities etc.
 - Links to other sites such as netbuddy and festival spirit
 - o Increase awareness of free activities in the community and local groups
 - Share positive examples and images of what young people can do eg waterskiing
- ➤ Residential schools/colleges/providers must prioritise an active and achievable activity/leisure programme for all young people, which includes regularly getting out and about in the community. This is essential to reduce the risk of isolation in residential settings and to reduce the likelihood of challenging behaviour due to lack of stimulation and boredom.
 - Use a book of pictures where appropriate to help young people choose what they would like to do

- Training for staff
- o Plan a regular programme of enjoyable activities
- Depending on the interests of the individual, this should include: sport, social activities, art, drama, church or religious groups, music, eating out
- Consider the role of pets for young people beneficial as companions and also for initiating social contact when out

> Transport options

- As part of an individual's package of support transport must be considered as vital to social inclusion
- Transport may include public transport where possible, motability car, car sharing for lifts, minibus driver for a group of young people etc