

Labels that disable – meeting the complex needs of children in residential care

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This paper is a practice based viewpoint grounded in the learning gained by the author from twenty years of delivering residential services to young people commonly regarded as 'difficult to place' or labelled as having 'complex needs'. The main arguments presented are that residential care has a unique and valuable role to play in providing stable care and treatment options for some children and young people in care, especially those regarded as 'complex' and that it is often not the children themselves who are 'difficult to place', but the system which makes it difficult for children to sustain placements by placing them inappropriately. Finally there are questions that need to be answered about how we find the 'best' form of care and treatment for these 'complex' children.

These themes will be addressed by looking at four questions:

- What is the role of residential care?
- How can residential care meet the needs of children with complex problems?
- How do we measure outcomes for complex children in residential care?
- What should the relationships be between mental health and residential care services to maximise benefits to young people?

Whilst the case studies which will be used to illustrate the points raised tell us much about what can be achieved with the most 'intransigent' cases when the right placement is found for them, they also raise much wider questions about the means by which young people are assessed and placed, how value for money is determined and what is our duty as a society to our 'most vulnerable' young people.

The title of this paper is 'Labels That Disable'. Professionals use a lot of different labels in their attempts to neatly classify looked after children into 'types' or 'groups' that can be allocated to specific types of care or treatment. Some of these labels are offensive to the young people involved. It is not uncommon to hear children described as 'difficult' or 'damaged'; professionals also disagree about whether we should describe the type of services we are speaking about as 'care' or as 'treatment'. The latter term can imply there is something 'wrong' with the child, and we are familiar with young people who resist anything that has a 'therapy' label on the grounds that 'I'm not **** mad'. Children are described as having 'behavioural difficulties' or 'dysfunctional behaviour'. These ideas are not particularly helpful in terms of thinking about why a young person has chosen a particular way of communicating their distress, grief, anger, frustration and fear. Behaviour is rarely dysfunctional, it has a function for the child and that function is usually connected firstly with survival, and secondly with communication. Understanding behaviour and assisting young people to find alternative ways of both surviving in a world that they have experienced as difficult and hostile, and communicating the nature of that experience to those around them is at the root of any successful intervention or 'treatment'.

For those children who have been classified as having complex needs, further terminology abounds. Children may have been labelled with attachment disorder, conduct disorder, eating disorder,

personality disorder etc. etc. or diagnosed as bipolar, OCD, depression and so on. It is not unusual to see notes written by clinicians describing children as ‘extremely dangerous’ on the scantest of evidence. How useful are these diagnoses and labels? Many of them carry stigma, and careless comments, once they become part of the ‘record’ can have significant effects for many years into the future. The words we choose to classify and describe how children are, or how they behave are only useful if they tell us something useful about how we should respond to the child and what we can do that is likely to be helpful to them. If a diagnosis has the effect of making the child ‘someone else’s problem’ or making adults fearful and uncertain of their own ability to cope with that child, it has not been useful.

What is the Role of Residential Care?

Residential care is often characterised as a dumping ground and a last resort for children who have experienced numerous broken placements. It is regarded as difficult to classify and one definition by Roger Bullock suggests that residential child care generally caters for children with identified cognitive or educational deficit, or a mixture of social psychological and behavioural needs, including those for whom these overshadow other needs including education¹. Bullock goes on to describe out of area residential placements as catering for “severe and complex behavioural problems where in house services have been exhausted and there is a continuing risk of harm and a need for specialist therapy.”

Thus residential care has a vital role to play in providing safe environments and opportunities to address areas of difficulty for many of the most vulnerable and complex children in the looked after system. The term ‘complex needs’ is itself over used with little thought as to definition, however a useful definition is that a young person who has complex needs experiences problems that are more than the sum of the various components which comprise their particular set of difficulties.

Young people may also find themselves in residential care as a result of a crisis or emergency placement. This is less easy to defend as these ‘crises’ are usually foreseeable and preventable.

Barbara Kahan refers to the therapeutic nature of children’s homes, and does not see ‘therapeutic’ as being exclusive to structured therapeutic communities but as something which resides in the relationships between children and residential staff and in the character of the day-to-day care being delivered². Residential care homes typically care for between four and six young people, following a trend spanning a decade or more towards smaller homes, with some more specialised settings caring for just one or two children. Young people questioned about their experience of residential care frequently refer to staff relationships as caring, supportive and parental. In fact many foster homes house more looked after children than smaller residential homes. It is high time we moved on from the debate about fostering vs. residential and moved towards an understanding of which children and young people are likely to benefit most from a suitable residential placement, and which can best have their needs met in a substitute family. Currently it is still common for children to have to journey through a number of ‘failed’ foster placements before they are considered for residential care. Thus they are unlikely to access the level of support and expertise they need until

¹ [Bullock, R *Residential Care in The Child Placement Handbook*, BAAF, 2009].

² [Barbara Kahan, *Growing up in Groups*, NISW, London, 1994].

the time they have left in care to benefit from it is short, and their inbuilt sense of failure and rejection has been further reinforced by the preventable sequence of fostering breakdowns.

What does residential care offer?

Many fostering schemes are now able to offer similar levels of 'wrap around support' to that which has hitherto been exclusively available in residential settings. Typically such support will include access to psychotherapists and/or psychologists for children and staff teams, additional support in school, or access to specialised school placements, on call advice and support and training for the carers. In which case it could be argued that with these additional inputs, surely any foster family can be supported to deal with the most challenging and complex of children?

Some young people simply do not wish to live in someone else's family. They may feel disloyal to their own family, whatever the reasons that separated them; they may be overwhelmed by a fear of rejection by a family (and if this fear is great enough the child will succeed at making it a self-fulfilling prophecy); their experience of families might be of such a toxic environment that nothing will reconcile them to the notion that a family unit can be a safe and loving place to be. It is also the case that the needs of a child who is in an almost permanent state of distress, heightened anxiety and internal chaos for structure, unconditional love in the face of the most extraordinarily hostile and rejecting behaviours, and total commitment, is simply too much for the most experienced and well supported family to cope with over a sustained period of time. The healing of a very troubled child also requires that the environment, expectations, activities and daily routines of the home are exclusively tailored to the needs of the child. Everything that takes place in the home will have a purpose towards the learning and development of new ways of thinking and being, every part of the structure and the rules will have a rationale that is connected to the aim of rehabilitation. It is simply too much to ask an existing family unit to alter every aspect of their life so completely as to accommodate the needs of a child experiencing the extremes of distress and turmoil in their lives, and many of the specific tribal rules and fetishes that we impose within our own home environments are often utterly unimportant and unreasonable, and thus far too much for that disorganised and chaotic child to deal with!

In a good residential setting the child can experience consistent structure and routine, emotional containment, predictability and planned effective responses to behaviours and emotions, as well as benefiting from specific clinical inputs and treatment based activities. The emotional energy required for residential child care workers to behave as these super consistent super parents in the face of extremely challenging situations is considerable; however it becomes possible when the emotional demands are shared between a team of adults.

Models of Care

It is almost certainly the case that the specific model of care adopted is far less important than the fact of there being a model of care that is underpinned by an empirical and theoretical evidence base, that the staff and young people are signed up to, and that is supported by both an established culture within the home, by sound leadership and supervision structures and by appropriate training and resources. In the setting from which these case studies have been drawn, the work was modelled on Transactional Analysis (TA). TA offers a comprehensive model for understanding both human development and communication and provides a relatively simple framework for teaching

both adults and children fairly complex concepts. TA is a popular and effective model for therapeutic communities (TC), having been used worldwide in both prison and adult mental health settings, as well as with children and young people. The care home from which the case examples are drawn is Bryn Melyn. Bryn Melyn began on a traditional TC model as a small group home, however in later years it was a pioneer of more individualised work for very complex children and gained a reputation for its work with children who would have exhausted all other approaches to treatment and intervention.

Intensive one:one work has faced criticism for failing to prepare young people for the ‘reality’ of living in groups. The psychological model underpinning the one:one approach is based on Jaqui Schiff’s Cathexis theory which is a ‘reparenting’ model. Children who have never had a successful relationship with an adult caregiver need to rewind to that formative stage of infancy where their only task is to form a trusting bond with a single reliable adult caregiver. From this successful base the child works outwards to develop successful relationships with others in the immediate care group, to friends at school, to wider social networks. A successful progression from functional dependency to independence is achieved. Typically the process requires three years of intensive work, building trust, relearning relationships and constructing a more positive self, internalising learning. Successful relationships are integral to the success of therapeutic work, and the relationships built during a positive residential placement can be every bit as positive, enduring and *essential to recovery* as successful relationships with foster carers. It is vital that this is better understood by policy makers and commissioners as current practice often seeks to minimise the cost of high tariff placements by planning to move the child into a less intensive resource as soon as their behaviour has stabilised. Stabilising the most extreme aspects of a young person’s behaviour is usually achieved towards the end of the first year (just as they begin to feel safe), thus the rush to move the young person on to a lower cost setting is both wasteful in terms of resources invested and damaging to the longer outcomes for young people who feel punished for doing well.

“One young woman, who had moved to a small residential placement, was keen to recognise the positive impact on her of the high staff/young person ratio. However she was alarmed at the fact that her placement might end: ‘...everybody wants me to move on because I’ve gone good now.’ (Young woman, 17 residential placement)”³

In a similar vein another young person interviewed about his placement stated “If I’m bad they move me; if I’m good thy move me!!”

A further area of concern relating to the importance of placement stability and duration is the lack of clear policy guidance in relation to the benefits to many young people of staying in their residential home until eighteen or beyond, in contrast to initiatives being piloted for young people in foster care.

Case studies – common themes

Eight vignettes are presented describing the presenting needs on admission and the progress of a selection of children referred to the Bryn Melyn children’s home in North Wales. Many of these children would have experienced lengthy stays in secure or psychiatric secure settings prior to

³ [Ward, H; Holmes, L; Soper,J; Costs and Consequences of Placing Children in Care, JKP, London, 2008]

referral. Many would have already been written off as young people destined for a lifetime of institutional care, be it in prison or psychiatric hospital, or chronic social exclusion. Referral to a 'specialised therapeutic setting' would have been seen as a last chance. Most exceeded all expectations of them at the time of placement. This kind of care would be regarded as 'high cost low incidence'. Placements in settings like Bryn Melyn can cost from £3,500 - £6,500 a week, compared to an 'average' residential placement cost of around £2,800 per week.⁴ In a report published in 2008⁵ the New Economics Foundation (NEF) calculated through their economic analysis that for every additional pound invested in higher-quality residential care, between £4.00 and £6.00 worth of additional social value is generated. In its 2005 report, *Transitions*⁶, the Social Exclusion Unit calculated that if young people leaving care had the same patterns of activity as their peers in relation to education employment and training the savings over three years would be £300 million. However there is at present no incentive for Directors and Commissioners of Children's Services to factor in these long term economic arguments when making decisions about making and breaking placements. Returns to the general exchequer at a national level do not impact on their local twelve month budget allocations.

The first set of case studies relate to young people whose primary 'diagnoses' were related to physical or intellectual disabilities or mental illness, or a combination of these. The second set is from a more general population, albeit at extreme ends of the 'difficult behaviour' spectrum.

Any reading of these case files would indicate that each of these young people was in serious difficulty early in their teens, and in some cases much earlier. All of them had to wait until they were in absolute crisis with no possible alternatives before a specialised residential setting was considered for them.

Each of the cases presented would be considered very high risk and high profile within their placing authorities. The stakes were high if the placement failed, or if the authority did nothing. In each case the work was enabled by a strong partnership between the residential home and the placing authority, a partnership founded on trust and cooperation, and a willingness to share the management of risk in situations where many would have balked at permitting such high levels of risk to persist in a non-secure setting. However the examples demonstrate that although risk cannot be eliminated, with appropriate management it can be contained. Without an element of risk complex young people may be denied the opportunity to live in an environment where they can begin to learn the practical and emotional skills they need to develop and grow and move towards a more hopeful future.

Any one of these eight individuals faced the possibility of lifetime incarceration – either in a psychiatric or a prison setting – at some stage in their journey.

Despite the extreme presentations, and in some cases clinical diagnoses, that these young people brought to placement, nothing that was done with them was much more than good structured

⁴ [this has been estimated from a number of different sources however it is very difficult to arrive at an average figure, partly because it is difficult to compare like with like when looking at in-house provision compared to agency provision – in house provision will be quoted net of true infrastructure costs – partly because aggregated figures collected for statistical returns group together all settings regulated under Children's Home Regulations – which includes hostels – and partly because individual analyses by local authorities often show only the net figures without including any contribution made by health or education].

⁵ *False Economies*, NEF, 2008

⁶ [*Transitions*; Young Adults with Complex Needs, ODPM, 2005]

consistent care, underpinned by individual therapy, a willingness to work with wellness and the whole person rather than just illness and diagnosis, and an unerring belief in the potential of each one of them to move significantly from the point they were at on arrival.

Appropriate clinical inputs were brought in and partnerships developed where they were needed however in dealing with young people who have been *assessed by multiple medical professionals and not had their holistic needs met through these channels* it becomes the responsibility of the specialised residential provider to hold the overview of the case and coordinate necessary clinical inputs. Health providers do not have ‘magic bullets’ to solve the problems presented by these complex children and many children arrive in therapeutic settings over medicated, and with other care settings having abdicated responsibility for them. This is how diagnostic labels can disable. They don’t just result in the young people being pigeon holed and directed towards services which can’t meet their needs (because they can do the bit on the label but they are not equipped to deal with the whole of the child’s presenting needs), care professionals and social workers are often disabled too as they suddenly believe that if the child is diagnosed with a disability, a disorder or an illness they become somehow ‘other’ and are no longer within the capabilities of social care. All of these young people need the basic structures of good care to support whatever additional inputs or pharmaceutical support might be required from health professionals. It is important that care professionals recognise what they have to offer these young people, and important too that health professionals recognise this and work with the care teams, who take the brunt of the child’s distress on a twenty-four seven basis, as equal professionals.

Unanswered questions

How do we identify the children and young people who can most benefit from specialised residential care?

How do we ensure children who are identified early on as having ‘complex needs’ find their way into suitable long term placements that can meet all of their needs as soon as possible?

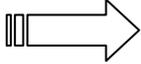
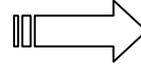
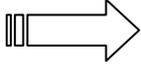
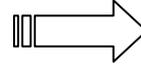
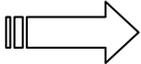
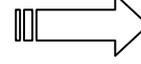
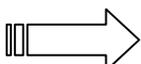
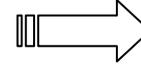
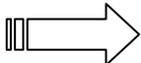
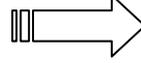
What should we be measuring to make a judgement about delivery of ‘best value’, and when should we measure it?

What is the moral responsibility of the state as corporate parent to secure the best possible outcomes for children looked after in public care, regardless of economic factors, or in the absence of measurable outcomes which can be universally agreed, to provide the best possible quality of life during the time that they are looked after?

Age and presentation on referral

Key milestones

Situation on leaving

					
<p>‘Lizzie’ 15</p>	<p>Childhood epilepsy, speech impediment, MLD, hemiplegic, partial wheelchair user extremely aggressive and violent, heavily medicated. Significant risk to self and others. Described as a serious danger to children.</p>		<p>Consistent team of selected male and female carers reduced from 3:1 ratio to 1:1 over time. Reduction in medication, improvement in communication/self esteem/personal appearance, reintroduction to education and improved relationships with family</p>		<p>Attending FE college course, is enjoying life, and has positive relationships with family and carers. Planned move at the age of 18 ½ to a supported living situation similar to the setup she has had at Bryn Melyn back in her home area to work towards a more autonomous living situation.</p>
<p>‘Loretta’ 15</p>	<p>MLD, foetal alcohol syndrome, aggression, violence, severe risk taking behaviour, self harm, highly sexualised behaviour, fire setter.</p>		<p>Consistent team of male and female carers reduced from 2:1 to 1:1 ratio over time. Improvement in self esteem and appearance, worked through major issues with her family, learned to make and sustain appropriate relationships with partners, attended college</p>		<p>Planned move at the age of nineteen to independence flat with floating support</p>
<p>‘Rosemary’ 17</p>	<p>Paranoid Schizophrenia and depression. Had experienced persistent recurrent ritual abuse as a child. Adult psychiatric ward ‘illegally’ detained. Had previously lived with grandmother who could no longer cope with her. Serious risk to self and others.</p>		<p>Developed trusting relationships with mixed gender team of workers in 1:1 setting. Mental illness brought to a manageable level with significant reduction in need for hospital admissions. Able to feel positive about her identity and participated with partial success in college, followed by a successful work placement in the fashion industry. Suicidal thoughts almost eliminated.</p>		<p>Age 19 ½ after a proposal to move her into independent living which she resisted, an adult placement was found for Rosemary in a supported semi-independent setting for people with mental health problems.</p>
<p>‘Marie’ 17</p>	<p>Adopted Romanian orphan. Diagnosed attachment disorder, MLD, Autism, Depression, OCD. Sensory integration dysfunction. Highly demanding controlling aggressive and violent behaviours. Heavily medicated. Excluded from school 2 years.</p>		<p>Work was carried out intensively on a 2:1 staff ratio reducing to 1:1 in the family home as it was felt that removal to a residential setting would re-traumatise her. We rejected nearly all of the clinical diagnoses and worked on setting boundaries and teaching appropriate behaviours and structures.</p>		<p>Able to acknowledge needs of others and relate appropriately to her mother. Aggression virtually eliminated, medication down to minimal dosage of just one tablet. Moved into her own flat close to mum at the age of 19 and manages most household tasks. Currently on reducing support and spends nights and weekends alone.</p>

The key to success with all of these young women was looking beyond their diagnoses and working with them as ‘whole people’. Addressing fundamental issues associated with family relationships and childhood trauma was instrumental in the progress made by all of them and this together with building resilience factors and developing their interests and personality was the focus of the work, not the disability or illness.

Age and presentation on referral

Milestones and situation on leaving

Journey post care

**‘Simon’
15**

History of absconding and firesetting. Is placed after eighteen months of ‘no progress’ in specialised secure unit. Described as dangerous and regarded as intimidating by staff, though no instances of physical violence. Out of school for 5 years. Functionally illiterate (IQ 60, reading age 8 years). Mixed race. Mother in the sex trade and has LD/MH. Father unknown

Made some good relationships with staff in 1:1 setting and managed to remain in placement longer than any of his previous 8 children’s homes. Some engagement in education. Some improvement in self esteem and progress from ‘hiding’ in coat and scarf to age appropriate dressing. However through a combination of continued petty offending and frequent breaches of bail due to absconding back to mum eventually ended up in custody.

Spent a brief period in a home for SLD post custody before being homeless. Unable to access any MH services despite diagnosis of BPD and chronic anxiety disorder. Is chaotic and suicidal receiving only support from former care home worker. Narrowly avoids a life sentence for arson after setting and extinguishing a small fire in a waste bin. By age of 25 is established in safe flat and outwardly presents as more stable. Remains socially isolated with no work, college place, family or friends.

**‘Peter’
15**

Mixed race young man who was traumatised by death of his mother when he was 5. Extended family cared for him until he was taken into care as an angry young man at the age of 10 and subsequently went through 8 placements being each time excluded for aggression and violence.

Builds good relationships with mixed gender team in a 1:1 setting. Attends school, makes friends in the community and plays football for local team. Thrives on individual attention and presents few problems in placement. Progresses to independence flat within residential setting and copes well. Is re-traumatised by violent murder of his cousin to whom he was close.

Under pressure from Leaving Care team returns to home area. Suffers rapid decline in MH and becomes depressed. Starts to drink heavily and always finds trouble when he is drunk. Is allocated a mentor but does not click with him and remains isolated. A series of scuffles eventually lead to him retaliating after a racist attack and as he was caught with a broken bottle faces a life sentence. Intervention from former key worker who arranges psychological assessment results in sentence reduction and on leaving prison enrolls in plumbing course. Has now given up drink, has a new flat in a safer area and is happy with life.

**‘Diane’
15**

Is placed in crisis after being illegally detained in adult psychiatric ward after an OD. Experienced childhood neglect and abuse and was carer to her two young brothers as mother was an alcoholic and could not take responsibility for children. Was denied admission to care on first presenting herself to Social Services despite disclosing abuse. On admission to care follows the example of others and starts to skip school, take drugs and go wild.

Very reluctant to trust anyone in early days of placement. Forms particularly strong bond with one of her 1:1 team. Begins to interest herself in books, life and current affairs although refuses at this stage to re-engage in formal education. Although quite chaotic in many ways and unready to engage in formal therapy Diane settles to a fairly uneventful placement, self harm ceases and she is able to grow as a person and develop her own interests.

Leaves care at 18 and moves away undertaking voluntary work for a year before enrolling on access course which she passes with flying colours before moving to London to attend university. Manages to get a good degree despite bingeing on drugs and alcohol. Faces up to the fact that she might be an alcoholic in final year of university. Spends three years travelling the world before returning and having a nervous breakdown. Holds down casual jobs, pursues voluntary work with children’s charity, begins writing career, is diagnosed bi-polar. Now learning to live with this.

**‘Colette’
15**

In care from age 10 following early abuse and by age 15 has spent almost three years in secure accommodation due to severity of self harm. Referred for placement at 13 but remained in secure and finally placed at 15. At her admission meeting SW is discussing preparation for foster placement.

Is liked by staff and makes good relationships with her team in her 1:1 care setting. Self harm is persistent and extreme and she often presents as dissociated. Significant levels of additional support provided to staff to manage their own emotions in relation to self harming. Placing authority agree return home just after her 16th birthday against placement advice. Senior manager request placement take her back on Boxing Day following incident. Staff ratio is increased to 2:1. Self harm continues at manageable levels and progress is made in all other areas. Emerging psychosis result in short admissions to hospital however placement is unhappy with treatment regime there and she comes back home. Recommendation for longer term treatment is accepted by authority but they cannot fund it so she is told she will have to leave on her eighteenth birthday. Devastated she packs her bags and leaves age 17 ½. Within weeks she is in a secure psychiatric hospital. Placement agrees to take her back but Health and Social Services disagree about funding split.

For a chaotic four years Colette spends significant amounts of time in psychiatric wards suffering from severe psychotic episodes, escapes, absconds, is briefly in an adult placement, and thereafter variously homeless, in hostels and refuges, using drugs and generally in a bad way. She begins to piece her life together and forms a successful relationship with a partner which is a big turning point for her. The relationship produces two children however the partner is controlling and psychologically cruel and is seeing someone else behind Colette’s back. Colette has a further breakdown and has a bad eighteen months before meeting her new partner, and taking up a professional apprenticeship. She moves in, takes an access course and enrolls on a social work degree course, becoming star student and class rep in her first year.

In each of these four cases a snapshot taken at 16 (‘5 good GCSEs?’), at 19 (not NEET?), at 21 (still in touch?) or even at 24 would have given a very false picture of potential and progress. Young people whose journeys have been as difficult as these will take much longer to work through the developmental stages of late adolescence and establish themselves as young adults. Situation at 25 – 30 would give better outcome indicators. None of them would have ticked any of the boxes in their immediate post-care years. All are now doing better than would have been predicted for them. Would they all be exactly where they are now at nearly thirty regardless of any intervention? All have maintained contact with key workers and managers since their placement. Was the placement a turning point? It is not possible to answer any of these questions for certain, although the enduring relationships suggest that for these four older care leavers their final and most enduring residential placement did give them something that they were able to take into adult life with them, and may we have helped them hold on through their difficult years.

