

WHY CARING PARENTS HAVE TO LIVE FOR EVER

Caring parents having a son or daughter with an intellectual or multiple disability need to live for ever because almost all services, **supported accommodation**, in-home support, respite day services, sheltered workshops, education, etc, etc cannot, at present, be relied upon to get it right for those with little or no ability to adequately advocate for themselves.

Just some of the reasons why (If you know more, let us know):

1. Clothes being mislaid or lost, even when clearly marked.
2. Wearing the same shoes all the time, especially runners (when has a range of shoes)
3. Washing quality poor - stains frequently not removed with Preen – woollens ruined in hot water, etc, etc.
4. Clothes not ironed, or consistently ironed.
5. Inappropriately dressed for the weather and environment.
6. Generally, poorly dressed.
7. Bed made up when wet.
8. Top sheet not consistently put on bed.
9. Manchester and towels in poor condition.
10. Meals poor – lots of takeaway
11. Cut lunches, for day activities, poor.
12. Poor grooming, including teeth cleaning and nail cutting.
13. Shoes not cleaned.
14. Reluctance to use generic services for medical, hair care, etc, etc.
15. Very little meaningful interaction, developmental and social activities – loss of skills.
16. Failure to make or attend medical and dental appointments – Not in the staff diary, no one read the diary, or no staff wanted to go.
17. Casual staff sent with resident to medical appoints, because regular staff don't want the bother

18. Staff infrequently attending a resident admitted to hospital.
19. Injuries frequently not noticed or reported.
20. Reluctance to treat minor abrasions and rashes.
21. Residents needs have to fit in with staff needs, mood and availability.
22. Delays in taking residents to a doctor (Example: Sector manager visiting a CRU on a Friday, observed a resident with a streaming cold. On asking when the resident will be taken to a doctor, the staff said, "On Tuesday when his key worker is back!")
23. The "Key Worker" is intended to represent the resident's interests with the service provider, especially where the resident has no family or effective family. Yet key workers frequently do little more than the average workers (staff). And the key worker's loyalty is naturally with their employer – the service provider.
24. A "Case Manager" is also intended to represent the resident's interests with the service provider. Again, the case manager is employed by the service provider!
25. Apart from parents, family and friends, there is no provision for purchasing or replacing items and equipment which would help to enhance the resident's lifestyle. The resident's finances build year after year, with the resident having few possessions. Whereas, most residents can benefit from such items as, a trampoline, an exercise bike, balls, talking toys, communication aids, TV, video recorder, drawing boards, etc, etc.
26. Staff loaned a resident's radio to another resident for an extended period, without consulting the parent of the resident to who the radio belonged. The resident to whom the radio belonged had no meaningful communications.
27. Staff threw all washing in together, into the industrial washing machine – colours, whites and soiled clothing!
28. Staff refused to soak stained clothes in Napisan, just sent it to the mother of the resident to deal with.
29. Resident's rooms and windows frequently dirty.