



A LIFELONG HOME IN YOUR COUNTY



A project to create a special home for your sons or daughters closer to home.



INTRODUCTION

This is a practical booklet designed to empower parents of disabled young people to lobby and help Local Authorities to find or build suitable accommodation for their adult children, as they transition out of the relative 'honeymoon' of education. In other words, how to go about finding a suitable home for your young adults – sons and daughters.

There is a chronic shortage of suitable places across the UK, with many parents worrying where their sons and daughters will live and how they will be looked after properly when they are no longer around.

This booklet is aimed primarily at those young people who are severely autistic, but it will hopefully be useful for other disabilities as well. If your young person can go on a bus unaided, then this booklet is probably not for you.

This booklet also follows the long and hazardous journey of The Simon Trust as this charity helped to set up what is known as Linden Farm in Alfold, near Cranleigh, Surrey. Owned proudly by Surrey County Council, visitors are in awe as to what has been built, and something similar may be possible in your county. It will not be an easy journey for you, but a worthwhile journey.

There are five essential ingredients for what we are proposing:

- Space. Spacious accommodation, single story preferably on 2-3 acres of land.
- In a suitable setting. Linden Farm is in a semi-rural setting on the edge of a large village where the residents can be part of that community and being relatively near transport links.
- Back in your own county, near friends and families. Popping in easily for a cup of tea is so important.
- On-site activities. A correct balance of meaningful things to do on-site as well as activities in the community.
- A safe and stimulating environment. Safe from risks such as busy roads

We will keep coming back to these essentials throughout this booklet. We will also often refer to the Young People as YP (although they will of course cease to be young as they go through their lives, but we are still early in our journey!)

On behalf of the Trustees of The Simon Trust, we wish you every success as you start this long and sometimes frustrating journey. We promise you that it is worth the effort. We succeeded with Linden Farm in Surrey and the blueprint is there for you all to replicate in some form or other.

Best wishes

Peter and Sally Lawrence

THE LONG SHADOW OVER FAMILIES

Currently local authorities have inadequate provision available for this cohort of people and with a growing problem as council finances are stretched.

- Many YP are currently accommodated outside the county and away from families. This is usually socially and politically not ideal.
- It can be costly for a council to meet the needs of a YP outside the county.
- There is the uncertainty, stress and anxiety over the destiny of extremely vulnerable family members living far away. There are also the travel distances and costs.
- Rights not being met – inequality of access to education, learning and development, health and care.
- Justifiable fears for safety and wellbeing – lack of in-county provision can lead to risks of poor care, potential abuse and wrongful restriction of liberty.
- Transitions between education and care can be fraught with unnecessary risks often leading to individual and family crisis.
- Family break-ups and sibling impacts leading to knock-on mental health issues.

Several individual stories. We receive these sad stories daily.

Cameron: age 18

Hampshire

Placed at a 52 week residential school in 2018, Cameron was doing well in an environment with a rich sensory diet, predictable routines, structured activities, personalised support, positive relationships and lots of visual communication.

However, Covid meant he stopped accessing onsite education in March 2020 and he became restricted to his residence. Then placed in a much smaller residence with more vocal children and no free access to garden space his mental health started to decline. Without this daily structure, aggressive behaviours increased along with anxieties. He lost interest in things around him, including eating and became weak, gaunt and malnourished (for which he still needs nutritional supplements and help to reach a healthy weight). A series of OFSTED inspections picked up concerns about C's welfare, and after 3 consecutive ratings of Inadequate, children were given 3 weeks notice of eviction. A provider for supported living in adult's services offered a place – far from ideal as C still needed an education, but there was no other option. Since he moved in (Jan 23), C does not leave his flat except to visit home. He has little more to do than listen to music and not a lot has been done to support him accessing things that would improve his quality of life. He is still without education despite his age and remains in an unsuitable living environment, unstimulated with no enrichment.

C's complex needs were identified as a young child. He was sent out of county away from family. What is sad is that there is still nowhere within Hampshire to meet his needs.

Harvey: age 25

Surrey

A delightful, lively and excitable young man but with the cognitive ability of an 8 month old baby and the physical strength of a challenging, hyperactive 25 year old who can be destructive, stubborn and often awake all night! 24 years without a full night's sleep and exhausting battles with Social Services/NHS, have nearly destroyed the family, mentally, physically and financially (especially when all respite was cancelled during C-19).

Eventually, Harvey moved to a house with 2:1 carers. However, neighbours soon complained about strange loud noises, repetitive banging and damage. Within months, the landlord served notice and no other suitable, affordable property can be found – so Harvey is being EVICTED WITH NOWHERE SUITABLE TO GO.

Louis: age 19

Wales

He was abused in a residential home. The residential home of 3 years was closed by Ofsted. Safeguarding issues with 24hour notice - which made him and 50 other YP with autism, homeless.

Spent two years in an emergency respite place with no access to education. Been given someone else's epilepsy and bipolar disorder medication. Currently living in Wales although has been served notice in his current placement.

Family is in East Sussex & want him closer to home.

Connor : age 21

Manchester

Currently living at home. In the right setting Connor can be the most caring, sensitive and helpful person you will ever meet. However, when he's not, his behaviours can be extreme and he can hurt himself and others. He has 2:1 support in the community and is attending College – but leaves in Sept 2024. The family dread the future – they have been through 80 housing provisions, but all would mean Connor would have to share a home with 3 peers or more and this would be a disaster for him. Trafford policy is they will not cater for single occupancy, so no social landlords will help.

There are no suitable settings and the local authority simply do not care because it would cost too much.

Ted: age 23

Hampshire

Behaviour escalated at 17 years, after restraint at SEN school. Had to fight to get suitable residential college placement during which time Ted dipped in and out of depression. Post-college, a Residential Care Home assessed and said they could meet his needs. Great first 6 months, then a safeguarding incident saw challenging behaviour escalate again. Noisy environment during day – so he withdraws to his bedroom. Activities have been withdrawn, no trips out etc. Hence, placement is breaking down and Hampshire have no appropriate or meaningful alternative.

Ted requires routine to feel safe and secure and activities to engage in to avoid boredom and depression, and to gain trust/relationships with specially trained staff.

Constant worry for family about Ted's future when they are no longer around to fight for him. It has been a never-ending battle to get appropriate placements. He has had a lot of bad experiences that have influenced his mental well-being and behaviour.

Looking for a forever home where he can feel safe and secure with activities to engage in that give him a feeling of achievement and worth. When he is at "baseline" he is a happy young man with many positive qualities, with the ability and desire to learn new life skills and engage in new experiences.

How to create that special home for your son or daughter

- **Proposal document.** As this is parent led, it is you the Parents who need to create your proposal document for Social Services. 20 or so pages need to spell out the problem and find a solution.
- **An executive summary.** What you are asking for.
- **Ideal number.** At Linden Farm there is capacity for 10 young adults in single and multiple occupation single story flats. 6 YP – 10 YP in your new home is a good number, bringing economies of scale.
- **Pen picture.** Detail the prospective residents. If they are identifiable, that may include a photo and a pen picture of their character, issues, history and needs. Ensure that you have

permission for the photo (actually asking the YP is best practice) and just use a first name for privacy issues. You have to make everyone aware that there is actually a need!
...if there is a ready-made group wanting a space in the same year, then they can all go in the one Proposal document.

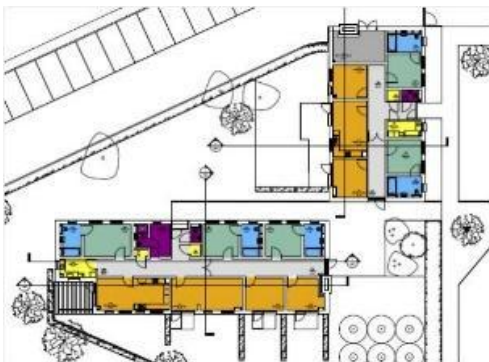
- **Public relations.** Very importantly you need to create a public awareness campaign of the problem with press, TV and social media, to highlight the issue to Social Services and the local community. Quotes from county councillors and MPs are very useful. You are clearly saying that there is a Need!
- **Land.** Identify several possible sites. It may be easier if they have an existing building footprint and located close to transport links. Your local land agent is a good first point of contact. You would need 2+ acres of land for a provision such as Linden Farm.
- **Space.** The main requirement is space. The five bed house on the outskirts of a large town is fine for more able autistic people. Your young people need space to let off steam and do activities on site. Parking takes up a lot of space as well.
- **Council.** Visit your Social Services with your Proposal. Work with them and not against them.
- **Finances.** You need to try to clearly demonstrate the hopeful cost savings with your Proposal that will help to offset the upfront build costs. Councils have little money at present.
- **Housing Associations.** Social Services may struggle with the construction, repairs and management of such 'homes for life'. Housing Associations may be the answer, but in all cases parents and Social Services must all work together to solve the problem.
- **Care Provider.** Social Services will tender for the Care Provider. You need to request that several parents are included in the selection process. The right Care Provider is essential for such a project.
- **Stakeholder Board.** This can be very useful to plan the construction and building details. Several representatives from Social Services, the architect, the landscape planner, several experts on autism and several parents all sitting down together regularly.
- **Supported living.** When the new 'home for life' is up and running, parental input is still vital. The Care Provider is there on a Supported Living basis and finding activities requires a close relationship between parents and the Care Provider. If your son or daughter has been in residential as a student, there is little to worry about with regards the concept of supported living. It does work fine, even for those previously in residential accommodation.
- **Charity.** Setting up a charity. This is not that difficult and provides an opportunity to raise money for the 'nice to haves' that Social Services will not provide. Find a friendly lawyer to do the work for you. The Simon Trust has donated about £200,000 for various activities at Linden Farm.

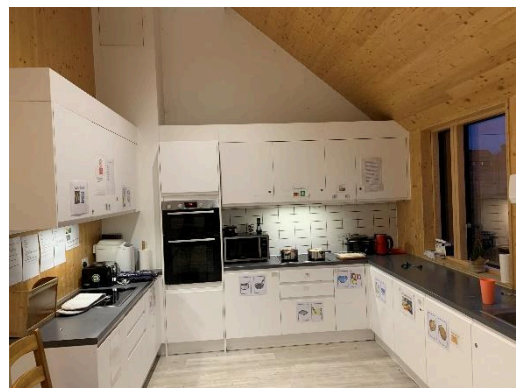
- **Activities.** This new home needs a careful balance of activities in the local community and on-site activities. Driver and staff shortages, bad weather, illness can necessitate the need for more on-site activities than one would think, and that the council may want.
- **Local community.** There may be misgivings from within the local community about your young person coming to live in their close knit community. However, work with them and a community can often welcome a care home into their midst.
- **Cars.** Each young person should be able to have their own car under the Motability scheme using part of their Disability Allowance.
- **Deputyship.** It is essential that you get this for Property and Financial Affairs and Personal Welfare.

Linden Farm, Alfold, Surrey

A proven model to replicate or part replicate already exists at Linden Farm in Alfold, near Cranleigh Surrey. Owned by Surrey County Council with Choice Care as the Care Provider.

- 5.5 acres Former farm unit
- Social Services and Parents working together
- Adjacent to a village and church on one side and open fields/woodland on the other side
- Provision for 10 profoundly autistic young adults.
- 3 accommodation buildings plus an Activity Centre/ Staff area
- 3 person shared unit – suitable for some individuals who can get on with each other
- 2 person shared unit
- 5 individual flats – suitable for other individuals who want their own cooking, shopping, activities etc..
- 19 parking spaces. These take up a lot of space.
- Staff sleeping accommodation in 3 person shared and 2 staff beds elsewhere
- Activities on site





HOUSE NEEDS

In any new development individual flats are fine for those more able. This might include a bedroom, an en-suite bathroom, lounge/diner and kitchen. Their own front door and access to a private garden.

There should be two means of entry/exit which is important. Your Social Services may request individual flats for everyone and you might challenge this.

Shared accommodation may be more suitable for those less able and/or for people with similar interests. A three person shared unit would have three bedrooms with en-suite bathrooms and a separate lounge nearby for each person for their own personal effects and their own TV. There would also be a lockable utility room, a communal kitchen, staff bedroom and visitor's toilet. Plus several storage cupboards for cleaning and sports equipment amongst many other things.

- Bedrooms should be in excess of 12 sq metres. More for wheelchair users. Remember that if someone has 2:1 care then there could be 3 people in a kitchen or bathroom.
- 56 sq metres internal for a flat is acceptable.

- Each flat needs a small private garden leading off the lounge for visiting families to sit in.
- Utility room with various cleaning products to be locked away.
- Coat and shoe racks by the entrance.
- Tough furniture (a brand) – lockable and durable
- Wide corridors or try and design out these wasteful corridors if possible.
- An external corridor linking the individual flats will help staff on cold/rainy nights
- Lighting as dimmable. Particularly important to assist with sleeping at night. Night staff will be walking around and they can wake residents up if sensors spring into action.
- Neutral colour paints and neutral fabrics
- Blinds are better than curtains. Curtain rails have a habit of being pulled down.
- Light and airy rooms. Linden Farm has very high ceilings with no loft space.
- Assisted technology in the bedrooms – listening devices that report back to the main office.
- Key fob front doors
- Plant Rooms for air conditioning, heating etc.
- Living in the Community – Housing Design for adults with Autism by Andrew Brand is an excellent booklet on room dimensions, paint colours, layout etc.



GARDEN NEEDS

- Swing and trampoline (ground level) are very useful assets.
- A large shed (10 x 3 metres approx.) with compartments for bicycles and gardening equipment. Bike hangers will save space, especially if there are trikes involved.
- Circular a 200 + metre track if your site has sufficient space. Wonderful for cycling, walking and letting off steam. 180 cms wide. Breedon stone gravel top.
- Space for a mower if your Council's contracted gardening company don't visit often enough.
- Important to keep flower beds and grass in good order for staff morale and set good principals for the young people. Litter needs picking up by the YP.
- Several benches and several picnic tables could be bought by the parents.
- Shade on sunny days is important. Umbrellas do not survive well, so a pergola is helpful to provide shade and give a focal point for gathering together. A size of 5 x 5 metres with a paved flooring and outdoor soft seating.
- Dumpy large bins may be better than domestic bins, as you will find there is sadly a lot of food waste which can attract vermin.

- Electric gates are vital at the main entrance if several of the residents tend to wander.
- Post and rail fencing is nice looking for around the houses and hawthorn and similar shrubs/trees on the boundary will help to hide any unsightly 5 foot high metal perimeter fencing. The image should be one of a rural setting as much as possible.



FINANCES

This project will only work if you are:

- Serious about doing a project, which will involve hard work over 2 years and inevitable disappointments along the way
- You have a cohort of 6+ people of similar age and ability/disability
- You have identified developers of larger housing projects (50 + homes) – pre planning permission
- You have got supporting quotes from local councillors and local MPs.

Our charity is willing to get involved with your project if you have done all the above. This is what we can do to help:

We are working with housing developers and local authorities across the UK to build new homes primarily for these young people with severe autism. The Labour government is committed to build many new homes over the coming years, so producing a lot of S106 money from the developers.

S106 obligations for larger developments require a certain amount of affordable housing, which can include C2 care homes of one sort or another. A new supported living care home needs to be included by the council's planning policy team for a particular larger development. Then agreement needs to be reached as to how much the developer has to contribute towards building that care home for either the LA or a registered provider?

What we can do to help: pre-application

- Meet with the Developer of 50 - 1000 houses. Checklist of:
- **Size** – does the site have 2 acres or more available for a new care home? This is what is ideally needed for 6-10 people. This requirement of size can often be an issue for a

registered provider to make a reasonable profit. Hence the need for the S106 contribution to help make the finances stack up.

- **Staffing** – the site needs to be near a reasonable size town with reasonable transport links
- **Space** – there is a need for plenty of parking, larger rooms, and on site facilities. Autistic people can get very anxious or frustrated and they need space to let off steam.
- **Noise** – the site should be a relatively quiet area and away from busy roads.
- **Plans** - we can help advise on layout with the developer's architect. e.g. room sizes, single story preferably, easy access to the outside, en-suite layout, storage (plenty needed), night staff facilities, office requirements, leisure facilities outside etc.
- **Planning application** - we would help prepare a 10+ page document to go with the application, to describe daily life, specific building features and the dire need for this sort of accommodation. i.e. make a case for the end-product. This document could go alongside the formal application.
- **Local authority** - we would offer to meet the LA along with the developer and discuss the plan, ensuring that they are happy with it all. Depending on the size of the development, the LA or registered provider may be gifted a care home from S106 money for part cost or no cost instead of the £6+ million that it might otherwise cost the LA to build and fit out. LAs have little money for these specialist and niche new homes, and it would be hoped that everyone can work together to make individual projects work.
- **Tenure** - as part of the LA's planning consent – finding a restriction in how the property is used i.e. for people with a certain disability – then this can be deemed as affordable housing. In other words, work with the LA to ensure we all gain the required consent and to ensure that the planning tenure is right.
- **The Need** - as mentioned above we would make a clear case for the need for suitable accommodation to various LAs – helping to provide a list of names (first name only for privacy reasons) and a brief CV of their issues/disabilities. We have already over 450 sets of parents across 27 counties, working in 'county teams' trying to get something built for their sons and daughters. We have numerous MPs aware of the shortage of accommodation.
- **Community PR** - we would attend any community meetings, to describe to the local community the value and importance of such a supported living home. The new residents need to be part of that community and be active within it, to whatever level they can manage. Simple litter-picking and if possible doing some volunteer gardening or running errands, supported by their care staff, will foster good relations with the community. This aspect is so important to seek community goodwill which may help to allay local fear of a lot of houses being built on their doorstep.

What we can do to help: after planning permission

- **Design** - we would work with the developer's architect to advise on all manner of detail. Flooring types, paint colours, type of glass in windows, heating, lighting, ventilation, door locks, type of stud walls, fencing, electric gates, suitable trees, sturdy garden taps, sensory room, hoists and hydro pools (if needed) etc. It is so important to get these issues correct in the first place. Breakages and damage are a major issue for those with severe autism.
- **Community PR** - we would be again available for any meetings. Good PR is so important for the local community, and this also ticks a social responsibility box for the Developer.
- **Local authority** - we would suggest another meeting to discuss who pays for the fit-out of the care home. Sturdy furniture, kitchen white goods, garden swings, tree planting and other

landscaping details. Some of these items may be for the LA to purchase or the incoming residents could be asked to contribute towards these costs.

- **Tenants** - as soon as possible, it would be useful to have a list of potential tenants from the LA. Specific needs for each tenant can then be met. Ideally the families of the young people should be within an hour of the new home. Further away and the phrase 'out of sight, out of mind' comes into play. Once established, the input from the families to the success of the new care home cannot be over-emphasised. Parents will be of great help and will play a big role in checking that the care home works as well as it should do.
- As building works start, we could be available for routine visits and advising on minor changes to any plans.

So, as a simple summary:

1. Use Council owned land if available
2. Find a cohort of similar YP who want to find accommodation in say 2027 – this process will take you 2 years.
3. The LA's planning policy team will tend to decide what the incoming S106 money will be used for – new roads, new schools, filling pot holes and at the bottom of the list may be a new care home. You need to get that new care home made more of a priority by emphasising the need- in any way you can.
4. Find a large housing Developer (50 - 1000 houses) before they go to planning permission. You need to sell them the idea of a new care home on the site of the new homes. So keep in touch with the developers as to what plots of land they have in mind to develop.
5. Some smaller building sites may not suit a new care home – space, noise etc. The S106 money can be re-directed to another quieter site that might work better for your new home.
6. S106 and Cil (Community Infrastructure Levy) are charges by the Council to developers, intended for social council needs. With 500 houses, the amount of S106 money can be huge.
7. The land owner and developer can have some say in what the S106 money is to be used for. Keep in touch with both parties.
8. With a developer building your care home, they already have boots and machinery on the ground to give a low build cost. They will need to sell the property at some point, and either the LA, or a registered provider may be grateful for an inexpensive and ready to use building. Modular buildings bring the cost of your new home right down and can make a very suitable and functional property.
9. Parents may volunteer to purchase the fit-out costs or you could raise money from small scale village events to purchase on site activities – swings, trampolines etc. Remember that you are all working together and some 'give and take' may be necessary on all sides.

FINANCES – USEFUL NOTES

Housing Benefit from Central Government should cover the housing element. The local council tends to collect the rent direct from the Government for the relevant county council, without the money touching your YP's bank account.

Council land. Councils have land banks ear marked for future schools, roads or care homes. To find 2 or 3 acres of this will save a lot of cost and hunting around.

Landowner acres. Alternatively one could lease land from a friendly landowner at a peppercorn rent for xx years. After the lease is finished, if the landowner wishes, they have planning permission in place for alternatives uses.

Housing Associations. They may take over ownership and pay for the construction. Also take over management, repairs and sorting out housing benefit administration for the Local Authority. They tend to be more used to building for the elderly where space and single storey structures are not so important. They have to make a profit to survive and it is important to ensure that the basic needs of space and an appropriate setting are not watered down too much if you get involved with a Housing Association.

Care companies. The larger ones do have property portfolios, and they may be the answer as to who buys the supported living homes after the developer has built it.

Wooden structures. There are companies making modular houses using Cross Laminated Timber or similar at prices like £250 square foot (£2,600 per sq metre). They are cheap and quick and easy to put up, but bear in mind future maintenance costs. It may be best to clad these structures with brick or stone so that one does not have to paint the outside every 5 years.

Maintenance. Repair costs when the site is up and running can be high. Toilet seats, shower equipment, windows etc. can get broken. Equipment needs to be as resilient and functional as possible. By experience, broken glass doors and windows take an age to replace.

Charitable donations. These are useful for the 'nice to haves' or fit-out costs, that a LA may not normally pay for. Local fund raising with cake stalls etc shows a willingness to work with your Social Services, even though they have a legal obligation to 'meet the needs'.

Charities. If you are serious, then set up a charity to raise larger sums. Setting up a charity with the Charity Commission is not that difficult, but find a friendly lawyer and be aware you do have to submit yearly accounts and reports.

Shropshire Model. Grant making Trust funds cannot give money directly to a government body. However there is the Shropshire Model where these trust funds give money to a charity, who then build/fit out and over the years, the buildings are gifted back to the council.

The Simon Trust may be able to advise further with this route. Autism is a high profile and well respected area for trust funds and significant sums of money are available to well prepared applications. The Wolfson Foundation and Bradbury Foundation are two of many trust funds.

Parental contributions. Many parents might expect to contribute towards the cost of buying a flat or house for their children as they grow up and get married. For anyone disabled, there is a tendency to let and presume that the State will look after them. To give money to your LA may set alarm bells ringing as to what happens if the LA closes it down for whatever reason. A donating parent should be able to protect themselves by buying a Share for perhaps £50,000, repayable with interest if the home is shut down. Ten parents x £50,000 each may make all the difference to a project happening or not happening.



What will be good about your proposed home for life?

- **Home for life.** Hopefully this does become a 'home for life'. You have put a lot of time and effort into helping to create something suitable for your sons and daughters.
- **Staff.** One of the most important features will be trained expert staff who can anticipate irregular behaviours. People who are trained in a particular disability and who understand the high-level complex needs of the residents.
- **Self-fulfilment.** An appropriate setting will provide an opportunity for the young adults to have a level of self-fulfilment, that they could never have in the 'baby sitting' environment that is present at many care homes. The semi-rural setting of Linden Farm has been so vital to providing a space which feels like it belongs to the residents, where they have the freedom of movement and can also be safe, and where they can tend their gardens and undertake projects to take ownership of the space. The new venture will have an infrastructure of activities which are suitable for autistic people. Growing plants, making saleable products and tending animals will be some of the many core activities.
- **Independence.** An opportunity to develop a degree of independence and personal care. The staff will encourage the young adults to do all sorts of domestic jobs, such as to load the dishwasher, clean their rooms, prepare meals and clean their teeth properly. Known as DLS – Daily Living Skills.
- **Skills.** An opportunity to build vocational skills. To see the YP wearing overalls, feeding the chickens, growing plants for sale and making things will be a great achievement. They will be doing something positive – even if only one greeting card is made in an afternoon.
- **Ability.** Over the coming years, it will become easier to judge what abilities and interests, the YP have. They may be called 'disabled', but if one delves deeper, they can be very able in certain respects. A first day at a new activity may last just a minute – one has to persevere and see what happens after time.
- **Space.** Many of the young adults have boundless energy and would not cope with a restricted environment. Easily unlocked doors and dangerous roads are inappropriate for them. Many hate noise. They can put fingers in their ears and they need space and a rural setting to bounce around in. They need a secure environment with easy access to safe space outside, for when they get frustrated.
- **Structure.** One of the fundamentals of the new venture will be that of routine and structure over which they have control. The YP will know what is happening each day with schedule boards and this structure will keep their anxiety levels reduced. Without structure, they can get very stressed – biting, pulling hair, gritting teeth and eyes bulging.
- **Communication systems.** The use of visual communication systems is often vital for communication for many autistic people who do not speak with conventional language. This

may be their only means of asking for the toilet or a drink. Effective communication support should be a cornerstone philosophy at the new venture. Speech and language therapists and occupational therapists would be available through CTPLD via the NHS on a regular basis, and used according to each YP's individual budget. Makaton is another popular means of communication.

- **Autism/disability specific.** We are keen that these young adults are in a peer group of people with similar levels of support, although with contact with the wider community. At Linden Farm we are autism-specific, with all residents also having learning disability and higher levels of need. Mixing up different types and levels of need often dissipates the best level of care and training, and may be inappropriate for these vulnerable people.
- **Training.** Staff will be trained in autism but also trained in giving the correct medicines at the correct time. In reality the best training is learning the habits and needs of the YP that the care staff are looking after – no book will tell you that.
- **Blueprint.** The blueprint of your future county project can be found at Linden Farm which is a smaller version of the wonderful Priors' Court near Newbury. Linden Farm is quite unique and visitors are amazed by what has been created by Surrey CC and various parents.

What will they do?

The essential ingredient of the semi-rural setting is that there is space for meaningful jobs to be done on site. Getting the staff interested and committed to these projects alongside volunteers from the local community is an essential ingredient to the project's success.

- Eggs to collect, animals to clean out.
- Plants to grow and vegetables to sell or cook for supper.
- Candles to make.
- Arts and crafts. Greetings cards. Pottery.
- Cookery lessons
- Bakery
- Woodwork.
- With all these activities, the young adults could have a level of self-fulfilment, a level of independence and can become part of the local community, instead of being forgotten and isolated.
- The parents and families will be important in making these activities actually happen, alongside the care staff.



A typical weekly activities schedule

Monday	Artventure. Baking on site. DLS Daily Living Skills
Tuesday	Trip to farm Bike ride on site every day 3-6 laps of the track
Wednesday	Allotment – planting, weeding, watering. DLS
Thursday	Sailability. Shopping. DLS
Friday	Swimming. Bird Club on site DLS
Saturday	National Trust visit. Disco on site.
Sunday	Comes home for lunch



Why are you doing all this?

“Everyone needs and deserves to have a role in society and to be recognised, or ‘validated’, for what they contribute. It is this validation that gives an individual a sense of worth, purpose and value. Also people learn by doing. You will only move forward in life if you are given the chance to participate, try out new things, learn from failure (and occasionally success) and move on. ‘Tell me and I forget, teach me and I remember, involve me and I learn” - the wise words of Benjamin Franklin.

For all the young people who are cared for by the state, there is an even stronger need for them to find their own validation in life; for them to realise they have a genuine value in the world and to be recognised for what they do is one of the most empowering things that can be allowed to happen to them. They must be allowed to contribute to society (in whatever way they can), learn from their involvement and be acknowledged by peers, friends and family for what they are doing. An approach to managing young adults with special needs, by bussing them out to various external events etc. does not meet the real need for them to be learning by doing and to be validated for what they contribute. It would be infinitely more important and constructive for them to be involved in activities that add value to society and put this at the heart of their personal development and care and ultimately to give them the chance to be validated as important individuals in the world. This ‘involvement’ is best done at their care home if there is space and the on-site facilities to do so, especially in these times of budget cuts and staff shortages.

Everyone has unique abilities and helping service-users understand what they bring every day to the work, groups, occasions etc. is so important. An individual’s contribution can be big, or may seem small, but it is uniquely theirs and valuable; it could be that they are great listeners, great enthusiasts, great huggers, great at remembering people’s birthdays, great joke tellers, great cooks, great at washing up, great smilers, great thinkers, great at getting stuff done, great planners, great hand-holders, great leaders, great followers etc. They bring so much more to the world than they realise - again this is a powerful (and often emotional) validation of who they are and what they do.

This is equally true for a group of people with special needs.



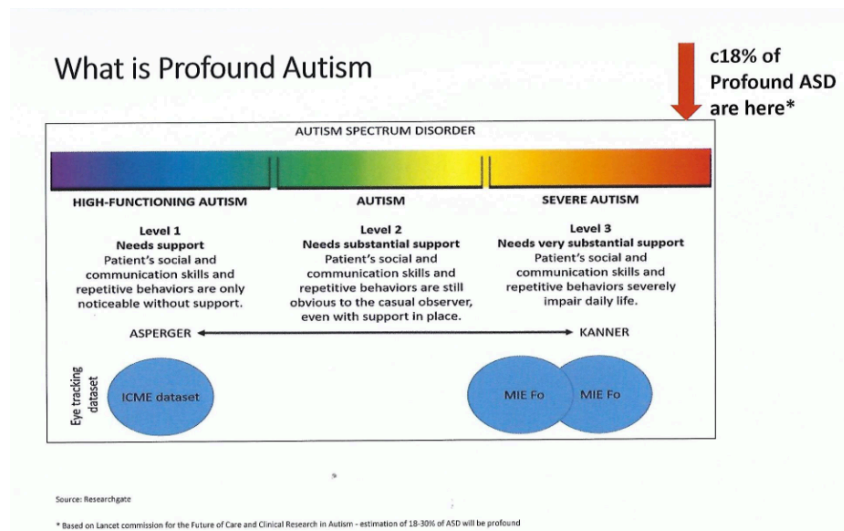
AUTISM

You need to find some fact and figures on autism from your council's statistics.

Level 1 Independent but needs some support

Level 2 Autism Needs substantial support

Level 3 Severe autism. Needs very substantial support. 18% of Profound autism are in this level.



There are also statistics available of those leaving education and going into suitable homes, going into unsuitable homes and going to live back in their own home. You need to find these.

Your council may also have a policy on Autism and how they are handling it. You need to read this and refer back to it. Your council will have spent a lot of time working on this document. What can you as a parent do to help this policy? Surrey CC for instance have 'An All Age Autism Strategy'.

CARE PROVIDER

- This is critical for the success of the project. Choosing the right Care Provider with a calibre of staff that will ensure that the young adults are well looked after.
- Levels of staff retention and involvement should be monitored with regular reviews to ensure that these key people are happy and motivated.
- The Care Provider is funded by Social Services, and they have to embrace all the red tape from CQC and other administrative bodies. Issues like fire safety, health safety, medicine handling and food handling. Often CQC will inspect the Care Provider's offices which is a peculiar strategy.
- Parents need to work constructively alongside the Care Provider, as their job is difficult and challenging at times. You need to work with the care staff and be ready to compliment them when you can.
- Long hours are to be avoided, as this will result in tiredness, stress, mistakes and staff loss. 12 hour days are more than enough. Staff need paying a fair salary which is a big political issue of present day.
- High levels of agency staff indicate staff problems. They arrive and do not know a particular person's characteristics, likes and dislikes.
- Many staff do not drive, so public transport is important as is taxi assistance from the Care Provider.

CARS

Each YP needs a car to get them to various external activities within the community. Funded by their care package via the excellent Motability scheme. Many garages operate a Motability scheme and despite lots of forms to fill in, the system seems to work well.

However having 8-10 YP cars on site with inevitable maintenance issues can become a major headache. Sharing cars may not be thought practically or socially correct by the Care Provider, but if possible, this can be a big saving in car parking space, cost and repairs/maintenance etc.

CHARITY

Setting up a charity is best done by a friendly solicitor. It is not difficult, but it needs a constitution and it needs a number of Trustees – several of which should not be parents. It also has to file annual reports to the Charity Commission. The Simon Trust for instance is a CIO – a Charitable Incorporated Organisation and since 2015 has organised over 85 fund raising events – cake stalls to large scale balls. This is hard work.

If you are serious, then set up a charity to raise sums of £2,000, £5,000 or £10,000 or so, using an excellent book called the Directory of Grant Making Trusts. (Costs about £100).

COMMUNITY

The local community will be wary of a new development coming into their town or village, and as parents you need to work hard to explain what is happening and that your YP can be a successful part of the local community.

Organising a coffee morning for the locals may help greatly as well as offering to litter pick or deliver the local Village News perhaps.

Attending church services and delivering hand made Greetings cards will help with any bonding with the local community.

COMPATIBILITY

Compatibility of the residents is very important. Can they get on together? Autistic YP can be very independent but then want to socialise when it suits them. If a group of parents can get together with a joint Proposal document with the intention of their children living together, then this is helpful and one keeps one's fingers crossed that all will be reasonably well. Altercations may well happen however. Matter of the Care Staff being one step ahead.

Obviously someone who is noisy does not want to live with someone who cannot stand noise. Someone autistic and likely to spring forward suddenly, does not want to be with someone in a wheelchair who cannot retreat quickly enough.

Residents should be of a similar age group and similar levels of ability. A new resident who is very disruptive or can show particularly aggressive behaviours may not be suitable for this type of project.

Reducing numbers to 4 or 6 young people can bring problems with economies of scale. Care providers may prefer larger units. Installing on site activities is easier if numbers are in the region of 6-10 residents.

Social Services may well do their own compatibility testing and they may well have the final vote.

COUNCIL

It is vital that those presenting this Proposal work closely with the Council and have a good relationship with Social Services. Find solutions together, particularly on the finances.

The Council is bound to provide what individuals need. A Duty of Care. Sometimes this gets forgotten and you as a Parent, need to sort out any issue.

Those items in your Proposed new home, that might be categorised as 'nice to have', could be provided by the parents via fund raising. Facilities and activities may fall into this bracket.

e.g. The Simon Trust is a local charity that has provided over £200,000 of equipment for Linden Farm. This is a huge sum and should not put you off fund raising for the odd garden bench or garden table.

Such a property that you are wanting to build should be a home for life. Council managements change with inevitable different priorities. Parents should work hard to support the council and make the new provision 'a centre of excellence for autism provision'. A high profile and well known provision with public support. Something that becomes very difficult to shut down for whatever reason.

DEPUTYSHIPS

Parents, or another suitable adult with capacity, should all become Deputies via the Court of Protection. There are two areas – Personal Welfare plus Property and Financial Affairs.

This is time consuming to apply, with many numbered COP forms to fill in. However it is absolutely necessary so that parents have an input on what happens to their children e.g. Deputyship allows parents to sign tenancies and other forms, as well as to challenge any organisation that does not have the YP's best interests in mind.

Cost is £371 each to apply, although there are reduced payments for those on low incomes. The process can take 3-6 months and can be done without the need of a solicitor, if one has the patience. There is also an Annual Duty Report to fill in each year – how has your YP got on?

Please Google Deputies on Gov.UK for full information.

JOBS

Finding some sort of job is going to be a ‘wonder moment’ for any parent. Severely autistic people can often surprise one with their levels of ability, if given enough time and support. e.g strimming a small patch of grass or using some shears to cut a few young shoots off a hedge are major triumphs.

DFN Project SEARCH is a transition to work programme committed to transforming the lives of young adults with a learning disability and autism or both – finding work for 1000 disabled youngsters every year.

LAND

Ideally you need 2+ acres to meet the needs of what you are wanting to be created.

Your local land agent is a good first port of call, or one of the big estate agents like Savills or Strutt and Parker. A disused farm or nursery are ideal ‘brown field’ sites as there has been some ‘use’ on this land already.

You might be looking for land on the edge of a settlement, with ‘connectivity’. i.e. not out in the sticks and hopefully near to some transport links to get staff to and fro. Check bus timetables for your Proposal Document.

Also ask your Social Services if they have any plots of land themselves. They will have land banks for future schools etc. This will save a lot of time and money if they will allocate this space to your Proposal. Councils can also help with planning permissions if there is a will on their part

NATIONAL HOUSING COMMUNITY OF PRACTICE

This is a national group led by the NHS/Local Government Association for all things housing related. Anyone can join their on-line meetings.

PARENT ASSOCIATION

When the YP are hopefully in residence, a parent association is useful to be set up. The meetings will decide on what new equipment to buy, fund raising, organising events and paying for insurance and maintenance on anything that they buy.

Most importantly keeping in touch with each other. Sharing problems and upsets.

The parent association needs a constitution, with its objectives clearly set out and may require a meeting every year.

It may be unwise for the parent association to get involved with individual care disputes.

PROPOSAL DOCUMENT

- This is what you are presenting to your Social Services. Perhaps 20 pages that clearly makes a case for a new supported living home in your county.
- This document needs great care and properly presenting in a binder and delivered by hand to a named person. Find a friendly graphic designer to make it look professional.
- On the front cover list names within your Social Services who you want to read this document.
- Describe autism and what is Profound Autism. There is a huge difference in ability.
- Why do they need specialist care? Challenging behaviours, absconding, safety, vulnerability, extreme sensitivity, physiological impairments etc.
- Current provision – what is available in county now or lack of it?
- The dangers of cost escalation from poor provision.
- Any stats on numbers coming out of education and going back to live at home, with resulting consequences. This is a powerful argument to ‘meet the need’ and to keep resulting costs down.
- Include any supporting quotes from MP’s and County Councillors. Many will be supportive of your cause.
- A map or drawing of the proposed site with a rough location of where the buildings and access road will go - will bring the project to life and concentrate minds.
- A proposed time scale for the project would help to keep the process moving, with your County Team and the Council.
- Photos – if relevant will also bring any document to life.

How to start your Proposal document

‘This document is a proposal to create a much needed home for eight severely disabled and autistic young adults with severe(profound) autism together with other disabilities in xx county. There is more information about each of these young people later in the document, but they all share a common need. That need is for a permanent home which provides the high level of support required to keep them safe whilst also allowing them to live healthy and fulfilling lives. A key ingredient to the wellbeing of these young people is for their homes to be close to family and friends.

This proposal is presented by xx county residents who are the parents (and main carers) of these disabled adults. These parents are keen to find a suitable home for their young people, so that they are close by and can continue to be involved in their lives. Places at homes like this, in xx county, are in short supply and so these parents are keen to work in partnership with xx council to improve this.

We have identified a site in xx town and propose a project similar to the very successful Linden Farm facility. The benefits of which would be:

- 1) Assist xx county in delivering towards its xx Autism Strategy
- 2) Immeasurable benefits to the wellbeing of the young adults and their families in providing a better life outcome for these young people and ready access to a family life.
- 3) Provide cost savings to xx county with a payback period estimated at xx years, with ongoing savings following, bearing in mind the lifelong care required.

The estimated upfront costs would be circa £xx m, but the ideal scenario is that this developments is delivered at a reduced cost to the Council, by talking with housing developers

Full details of our Vision, The Need, Proposed Project and Benefits to both xx county and the Young People in question follow, together with indicative costings and financial summary’.

PUBLIC RELATIONS

This project needs as much publicity as possible, to engender community support and political backing. It is important that the public understands the difficulties of these vulnerable, autistic young adults, and rallies round to help. These people must not be isolated but incorporated into the community, with as much help and support as possible.

Suitable targets for help are:

- BBC local TV – to cover the need and the lack of suitable provision
- Contact your local MP’s. Ask them to write a few lines of support for your Proposal document
- Contact your local county councillors -and ask for a few line of support
- Contact any local celebrities who have talked about autism – ask for their support.
- Village shows, village quiz nights and other local events – make mention of the need.
- Contact your local newspapers to cover the need and the lack of suitable provision



Below are two comments from local councillors and MPs who made helpful comments for a recent Proposal. You need to find similar people in your county.

“This is a wonderful and much needed campaign to find suitable homes for so many severely autistic and vulnerable young people as they leave education and need to find a suitable supported living home - with plenty of space, activities on site, near their friends and family and in a semi rural setting. There is such a shortage of suitable housing like at Linden Farm, and any help in finding finances to help pay for this accommodation is very welcome. There are many Surrey parents worried as to what will happen with their sons and daughters, as they the parents get older.”

“I am so pleased to have been asked to support this project.

As someone who worked in the field of Learning Difficulties and Autism for over 30 years It has been gratifying to see that people with difficulties are being seen as someone to be supported

To look after their own lives rather than having them looked after for them.”

SPECIAL REQUIREMENTS

Hoists Specialist information is needed here.

Wheelchair access These may well be needed.

Hydrotherapy Again specialist information is needed here.

Communication system so everyone can communicate with staff and each other. Depending on level of need this might include support with verbal communication, signing, use of electronic communication aids, and/or pictorial language systems.

Physiotherapy.

Sensory room. This is an important piece of equipment especially for autistic people who can spend enjoyable hours in a well managed sensory environment. The equipment is not cheap and one needs someone to manage and oversee all the equipment. Remotes get lost and batteries go flat leaving things not working properly. Care staff on 1:1 duty, often do not have time to prepare the room and switch things on before the YP loses interest and runs off.

STAKEHOLDER BOARD

As the project evolves, an advisory group sitting regularly is very helpful.

Made up of several parents, several independent experts on autism and representatives from the Council.

To meet every few months at council offices to discuss layouts, furnishings, flooring, landscaping and details like light switch design.

Meetings to be chaired by the Council and minutes taken.

All working together to create something special and unique. A centre of excellence is what you need to aspire to.

SUPPORTED LIVING

Many educational establishments are residential. The move to supported living should not be feared by parents however. There are very few practical differences.

Supported living is preferred by many as it allows adults their own flat in a community setting. With perhaps their own front door and garden.

Supported living has more legal rights for the tenant. Residential has less choice and control.

Supported living is preferred by councils as the housing benefit is paid by the Government. In residential, Social Services pay for the whole package.

TIMESCALES

To put down some actual dates, or seasons, will help concentrate the minds of councils and yourselves. This whole project is not a quick process.

Date: Find similar potential young people.

Date: Public awareness campaign

- Date: Find suitable land and a developer
- Date: Approach the Council with a viable proposal document, showing cost savings
- Date: Appoint architects
- Date: Start building
- Date: Start fit out
- Date: Gradual occupation of the new provision!

TRANSITION

When to start. Leave plenty of time to inform your YP that a change is afoot.

Communication. This is very important – social stories, photos etc. Visit the new home with people that the YP knows.

Speed. Go at the person’s own speed – don’t rush it.

Viewpoints. Involve as many people as possible – involves different perspectives and backgrounds

Persuasion. Make it worth the person’s while – make the move attractive to the YP moving.

Clarity. Be explicit/clear about everything – what exactly will happen.

Supported living – describe what will happen as they come out of residential or a school environment and meet new challenges.

VISION

Collaboration between local authority, charity and parents to provide long term supported living, in county and close to families, for extremely autistic adults, saving Council money while eliminating serious health and care risks.

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OPPORTUNITY

Use existing land to build specialist provision to reduce running costs.

Use an existing model developed by Surrey County Council to reduce risk and costs.

Enable profoundly autistic adults to live closer to families.

Share set up costs with charities, trusts, developers and interested parties.

WHAT NEXT

To date we have over 450 sets of parents across 27 counties involved in this campaign. Plus delegations from Singapore, New Zealand, Ireland, Abu Dhabi and Barbados who want to set up something similar in their countries. Every day we receive new requests for help from worried parents.

- Contact The Simon Trust by email and we will put you in touch with others in your county. Thesimontrust.org@gmail.com
- Please give a brief description of your young person (20 – 40 words including age) plus your county or London Borough – primarily your Funding Council. Plus your mobile if you want to go on the National WhatsApp group for general chat.
- Then it is up to you to communicate with your County Team and to get something built.

- This is not for the faint hearted and may take you 12 months to even get to the Planning permission stage. But with our autistic children, nothing has been simple - as we all know.

