

SUPPORTING PEOPLE WITH AUTISM TO LIVE THEIR LIVES

**Supporting someone with a severe
learning disability and autism to stay in
the community**

Laura

Background before support

Laura is 18. She enjoys going out for drives and loves music and animals. She is close with her family and we think she would like to live in her own home and go on holidays by the sea. She is 'borderline diabetic', has autism and a severe learning disability.

She moved to a residential care home which promised 'specialist support' six months ago when her mum and dad reluctantly agreed to a move as Laura's behaviour was having a detrimental effect on her 13 year-old sister, Lucy. They feel very guilty about this decision and they are visiting less frequently as its two buses away and they find it very upsetting to see Laura there.

When Laura becomes overstimulated by lots of people around her, noise or 'fuss' she becomes distressed and sometimes screams, grabs or slaps people who are near her. She needs essential personal care to be carried out and often this triggers incidents where Laura gets upset and staff get hit or scratched by her.

Laura does not use speech; she can use picture cards to communicate. People who can communicate with Laura, and who are aware of her sensory needs and cues, find that she can be very affectionate and loving.

Laura has PICA. She picks at the soft furnishings and pulls out bits of thread or her own hair to mouth and swallow. This damages her gums and she has had hospital admissions to remove obstructions. This has also caused considerable damage to the furniture in the home. Other residents in the home find her behaviour distressing and there have been complaints to the manager from their relatives and carers. Laura's hands, hair and clothing often have saliva on them which many staff find unpleasant and it seems to affect their ability to build a relationship with her.

Laura doesn't have a regular sleeping pattern, sometimes she's awake and 'singing' (making noise) during the night and during the day she spends a lot of time sitting alone and dozing as staff tend to leave her to her own devices to avoid conflict.

Laura only eats sugary foods. She spits out any food that she doesn't like. Staff have been told that she shouldn't have sweet foods due to her borderline diabetes and poor dental health, so each mealtime becomes a battle, with staff feeling at a loss.

Laura finds appointments with dentists and hospitals very traumatic and this has resulted in her been restrained and sedated for treatment.

The residential care provider now feel that they are not able to meet Laura's needs and that she should be moved to a more 'suitable' placement. There are no other providers willing to support Laura in the local area.

The skills, competences and knowledge to make a positive change

Social Worker

Laura's social worker recognises that she is at risk of an unnecessary admission and arranges a 'blue light care, treatment and education review'. A multi-agency review that puts plans in place to prevent things from getting worse. In addition he arranges additional short term 1:1 support.

Intensive Community Support Multi-Disciplinary Team / Behaviour Support Team

The team work with Laura's existing home to use Positive Behavioural Support (P.B.S.). It helps them understand why the behaviours happen and work with Laura and people who know her well to improve quality of life and reduce things causing distress and associated behaviour. A Positive Behaviour Support Plan is developed including proper assessment and planning to meet her essential personal care in a safe and positive way. Staff are trained and mentored to implement the plan.

Her team take a multi-disciplinary team (MDT) approach to primary and secondary care to meet her ongoing needs. **The occupational therapist** completes a sensory profile and advises on aids and adaptations for Laura's home and to enable her to carry out part of her personal care and reducing the amount of physical contact that her personal care needs involves. **The dietician** advises staff on foods which are a compromise between the food that Laura can eat and will eat. **The speech and language therapist** works with Laura to develop aids and systems to improve her ability to communicate. This allows her to understand her personal care better and have choice and control over when it happens and who does it.

It's obvious that Laura struggles with a lot of people sharing her home and that a small place near her parents is more appropriate. The social worker applies for a housing and disabled facilities grant and liaises with the local authority housing department. He also meets with her family to think about the type of support Laura needs and whether a direct payment could help.

Local Authority Commissioner

The social worker discusses the issues and the current gaps with the commissioner. The commissioner understands the long-term benefit of meeting Laura's needs and agrees to additional support in the short term. She works with the social worker, the wider multi-disciplinary team and the housing department to identify possible accommodation, including the specification of the property to meet Laura's needs. She also begins the process of identifying suitable care providers with the right skills who may be able to provide the longer-term support to meet her needs.

Laura's Family

Laura's Mum, Dad, Sister and Grandma continue to have an important role with their in-depth and long-term knowledge. They are involved in all big decisions such as recruiting support workers.

Housing Worker

A suitable flat is found for Laura so that she can live in her own home where she can have choice and control over her environment and less impact on others. She has her own personal space and front door, but it's within a larger building so there are staff available 24/7. For this to happen the housing team need to have the knowledge and skills to understand the environment that Laura needs, and the long-term implications of failing to meet her needs now.

GP and Community Dentist

A plan is developed with Laura to help with any future hospital admissions and dentist appointments. Technology such as using photos and Skype are utilised with her GP and dentist to minimise the number of additional examinations that she has to undergo and sedative medication, home visits, carefully scheduled appointments and noise-cancelling headphones are used to make those appointments less distressing.

Community Support Provider

Laura is supported by a consistent team of personal assistants who have had the right training to provide high quality care and support, get to know her well and hold her in positive regard. Laura has a mobility car which the staff can all drive. They understand the importance of family relationships and help Laura's parents so they can see her frequently for short periods of time, building a more positive relationship. The provider has an **in-house** positive behavioural support t/ trainer and in house advisors on activities and active support and ensure that her positive behaviour support plan is regularly reviewed. Laura is supported in activities in her home including household tasks and hobbies using Active Support – where her staff look for every tiny opportunity for Laura to be engaged and active. This starts with just a few minutes duration of any activity in order not to tire or overwhelm Laura – using communication systems to enable her to indicate when she wants to stop.

The Support Provider links with 'good gym' (<https://www.goodgym.org/>) to find Louise, a local student who becomes a **volunteer befriender**; calling in and spending ten minutes chatting with Laura and listening to music a couple of times a week. Louise uses online training videos to understand more about autism and pica.

Outcome achieved for Laura

Laura avoids an unnecessary hospital admission(s) and instead has a sustainable living and support situation that is personalised.

Supporting outcomes

- Laura's family are involved in her life and are supported in their relationships with her.
- Laura's physical and dental health is improved.
- A reduction in the frequency, duration and intensity of occasions when Laura is distressed and screaming, slapping and grabbing people.
- Laura spends more time doing activities she enjoys.
- Laura's interactions with staff support workers are more positive.
- Laura's care plan is regularly reviewed so her support can meet her current and ongoing needs. The benefit of having the right support to avoid regular or long-term expensive hospital admissions is recognised by both social care and health care commissioners