

# Supporting people with a learning disability and/ or autistic people

## Worked examples to support learning and development

### What are these worked examples?

These worked examples are based on real life scenarios of people with learning disabilities and/ or autistic people, who display or are at risk of displaying behaviours which challenge. Each worked example explains what workforce that individual needs, what skills and knowledge they need, and how much this training would cost. They can help adult social care commissioners and employers to plan support and provide the right learning and development.

Find out more and download other worked examples at [www.skillsforcare.org.uk/workedexamples](http://www.skillsforcare.org.uk/workedexamples).



### Meet Laura

Laura is 18 years old. She enjoys going out for drives, listening to music, spending time with her family and animals, especially dogs.

She has type 1 diabetes, autism and a severe learning disability.

As a child her parents, Janet and Peter, wanted her to live at home and for her to attend school. However they could not manage her behaviour and were concerned about the impact that Laura's behaviour was having on her 13 year old sister. They reluctantly agreed that she would live in a specialist group/ residential care home six months ago. They feel very guilty about this decision and talk about having 'sacrificed' one child for the sake of the other.

Laura has no speech and uses Picture Exchange Communication System (PECS) to communicate. She often gets frustrated and distressed when she can not get her message across, and displays this by kicking, screaming and banging her head repeatedly.

This particularly happens when staff support her with personal care. In the past she has injured herself and staff.

Laura does not have a regular sleeping and waking pattern. Sometimes she does not sleep at night, and sings or makes noises. During the day she spends a lot of time sitting alone and doing nothing, so she often dozes off.

She has Pica, an eating disorder, and eats things with a 'stringy' texture, including her own hair. This has led to several hospital admissions for intestinal issues and her gums are damaged from pulling hair backwards and forwards through her teeth. Her eating disorder means that her hands, hair and clothing often have saliva on, which some staff find unpleasant. She also picks at furniture in the home, and other residents and their relatives have complained.

People who can communicate with Laura, particularly her grandmother, find that she can be very affectionate and loving. Sometimes her grandmother is the only person who can calm her down. She does not have any positive relationships with the staff who support her - they tend to 'leave her to her own devices' so she does not get upset or angry.

She has had a sensory assessment but staff do not feel confident to implement the recommendations from it. Staff report feeling 'scared' of her and are not suitably trained and experienced to cope, and the current provider feels that they are not able to meet her needs. They are demanding that she is moved to a more 'suitable' placement, but there are no other providers willing to support Laura in the local area.

## **What are the key challenges that Laura faces?**

- Laura is at risk of an admission to hospital or inpatient services if they can not find a suitable service.
- Laura is at risk of losing touch with her family. They visit when they can but it is two buses away and they find it very upsetting to see her there.
- There is no real long term plan for her adult life.
- Laura needs a consistent and committed staff team who understand her needs, methods of communication and can provide her with some quality of life.

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## What could Laura's future look like with the right support?

With the right care and support Laura can have a positive future. Here is how this could be achieved.

- Laura is supported by the local housing team to find a suitable flat so she can live by herself and have more control and choice over the environment. The flat is in a larger building with staff available 24/7.
  - Laura is supported by a team of care workers who understand her behaviours and sensory needs, and receive the right training to support her. This includes a consistent team of people who get to know her well and are paid above the local rate for care workers. They get funding and access to a car to support Laura to engage with community groups.
  - She has a multi-disciplinary team who do a person-centred assessment of her care and support needs. This includes positive behavioural support (PBS), occupational therapy, sensory support, dietician, speech and language therapist, housing and disabled facilities grant, and intensive support from learning disability teams. They do a sensory profile and functional analysis to develop a care plan, which includes a PBS plan. They work with Laura to develop aids and systems to improve communication beyond what PECs enables.
  - Care workers support Laura to do activities in her home including household tasks, personal care, crafts, listening to music and dancing. They use an active support approach to do this. This starts with just a few minutes of any activity so she does not get tired, and then build it up over time. She starts going to a local gym and meets Louise, a local student, who becomes a volunteer befriender and visits Laura a couple of times a week.
  - The support provider gives Laura and her parents lifts to see each other regularly, so they can continue to have a positive relationship. They are involved in planning and reviewing her care and support.
  - Laura's team work with her to plan for future hospital admissions and dentist appointments. This includes using technology, such as photos and Skype, for GP and dentist appointments.
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## What workforce does Laura need?

To have a positive future, Laura needs the right workforce in place. Here are some suggestions.

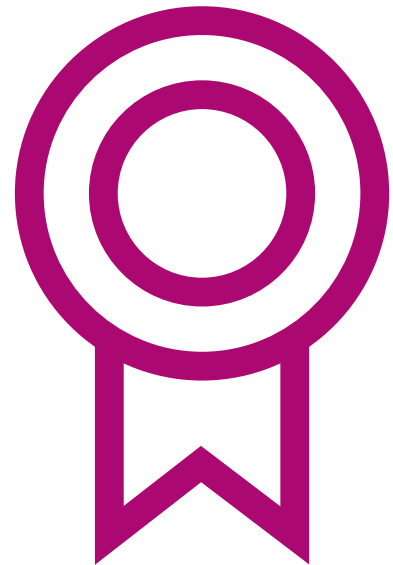
- Specialist community support provider, whose team includes:
    - care workers
    - team leader
    - PBS consultant
    - community activities provider
  - Family and friends
  - Social worker
  - Community learning disability nurse
  - Local commissioner
  - Independent mental capacity advocate (IMCA)
  - Occupational therapist
  - Speech and language therapist
  - Housing services
  - GP and practice nurses
  - Specialist dietician and diabetes care team
  - Dentist
  - Community pharmacy staff
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## What skills and knowledge does this workforce need?

Laura's workforce need to have the right skills and knowledge to provide high quality care and support. We think these are the key things that her workforce need to know or have skills around:

- person-centred care planning
- understanding behaviours which challenge
- PBS level A\*
- PBS level B\*
- autism awareness
- Pica awareness
- diabetes awareness
- PECS
- active support.



The table on the next page explains what skills and knowledge each worker needs. The boxes with a 'x' in suggest what that worker needs to know. The boxes which say 'some' indicates that some workers in this group would need this knowledge but not necessarily all of them.

All training should be delivered in the context of Laura's needs, interests and preferences.

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### Values

Everyone working in adult social care should have the right values. Values are the things that we believe to be important, and they influence how people behave in different situations. Recruiting people with the right values can help employers find people who know what it means to deliver high quality, person-centred care and support.

Our '[Example values and behaviours framework](#)' describes some of the values that are central to providing high quality care and support.

\*PBS levels A, B and C refer to the competency levels in the PBS Academy Competence Framework. The framework outlines the things that you need to know and do when delivering best practice PBS. It explains the competencies at three different levels: 1. direct contact (PBS level A), 2. behaviour specialist, supervisory or managerial (PBS level B) and 3. higher level behaviour specialist, organisational, consultant (PBS level C).

	Person-centred care planning	Behaviours which challenge	PBS level A	PBS level B	Autism awareness	Pica awareness	Diabetes awareness	PECS	Active support	Resilience	Specialist skills and knowledge
Laura	X	X	X		X	X	X	X	X	X	
Care workers ( from community care provider)	X	X	X	X	X	X	X	X	X	X	
Team leader		X		X		X	X	X	X	X	
Community activities advisor					X	X	X	X			
PBS consultant					X	X	X	X			PBS Level C
Families and friends	X	X			X	X	X	X	X	X	
Social worker	X	X	X	X	X	X	X	X	X	X	
Community learning disability nurse	X	X	X		X	X	X	X	X	X	
Commissioner	X		X				X		X		
Independent mental capacity advocate	X	X			X	X	X	X	X		
Occupational therapist	X	X	X		X	X	X	X	X		
Speech and language therapist		X			X	X	X				
Housing services		X			X	X					Environmental needs



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## How much would this training cost over a five year period?

This table estimates how much it would cost to deliver this training. It is based on the training listed on the previous page and the costs are estimated for a five year period. We recommend that a lot of the training can be delivered together, with people from different roles.

We have NOT included the basic professional training that roles like GP, occupational therapist and social worker do.

We HAVE included basic training that Laura's day to day support team need since they would be selected to support her specifically.



	Days of training	Number of people	Cost each day of paid work	Direct cost of training	Total cost	Cost of updating annually	% of their time spent supporting Laura	Cost related to Laura over five years	Cost related to Laura over one year	Notes
<b>Laura</b>	8	1	£0	£0	£0	£0	100%	£0	£0	Direct costs included with care workers.
<b>Care workers (from community care provider)</b>	7	14	£120	£4000	£15760	£5000	100%	£20760	£15760	
<b>Team leader</b>	6	3.5	£125	£0	£2625	£800	20%	£685	£525	Direct costs included with care workers.
<b>Community activities advisor</b>	2.5	1.5	£125	£0	£469	£150	0.2%	£1	£1	Direct costs included with care workers.
<b>PBS consultant</b>	54	1.5	£188	£8000	£23188	£600	1%	£238	£232	
<b>Families and friends</b>	6	3.5	£0	£25	£25	£10	100%	£35	£25	Direct costs included with care workers.
<b>Social worker and community learning disability nurse</b>	6	2.5	£146	£0	£2188	£500	2.5%	£67	£55	Direct costs included with care workers.
<b>Commissioner</b>	2.5	2.5	£229	£0	£1432	£250	0.5%	£8	£7	Direct costs included with care workers.

<b>Independent mental capacity advocate</b>	4	1.5	£175	£0	£1050	£200	0.4%	£5	£4	Direct costs included with care workers.
<b>Occupational therapist</b>	4	1.5	£146	£0	£875	£100	0.25%	£2	£2	Direct costs included with care workers.
<b>Speech and language therapist</b>	3	1.5	£146	£0	£656	£150	0.25%	£2	£2	Direct costs included with care workers.
<b>Housing services</b>	2	1.5	£175	£0	£525	£100	0.1%	£1	£1	Direct costs included with care workers.
<b>GP</b>	1.25	2.5	£563	£150	£1908	£600	0.4%	£10	£8	All dependant on prior expertise and experience.
<b>Dietician and diabetes care team</b>	2	2.5	£175	£0	£875	£250	0.1%	£1	£1	Direct costs included with care workers.
<b>Dentist</b>	2.5	1.5	£250	£0	£938	£180	0.03%	£0	£0	Direct costs included with care workers.
<b>Community pharmacy staff</b>	2	1.5	£175	£0	£525	£105	0.1%	£1	£1	Direct costs included with care workers.
<b>Total costs related to Laura</b>								<b>£21817</b>	<b>£16623</b>	
<b>Average per year related to Laura</b>								<b>£4363</b>		

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## What could Laura's future look like without this care and support?

Without the right care and support, these are the negative kinds of things that Laura might experience.

- Laura's team change frequently and there is no continuity of care. This means that they do not understand her care and support needs or how to communicate with her.
  - Laura continues to have a poor diet and ongoing issues with her health as a result of her diabetes.
  - Laura is admitted to hospital quite regularly (as a result of Pica, diabetes complications and self-injurious behaviour). Each time they find it challenging to agree a discharge plan for her. She finds this distressing and staff sometimes use restrictive practices.
  - Eventually she is admitted to a specialist hospital several hundred miles away from her home area at a high cost.
  - Her relationship with her family deteriorates as they find it too distressing to visit her.
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