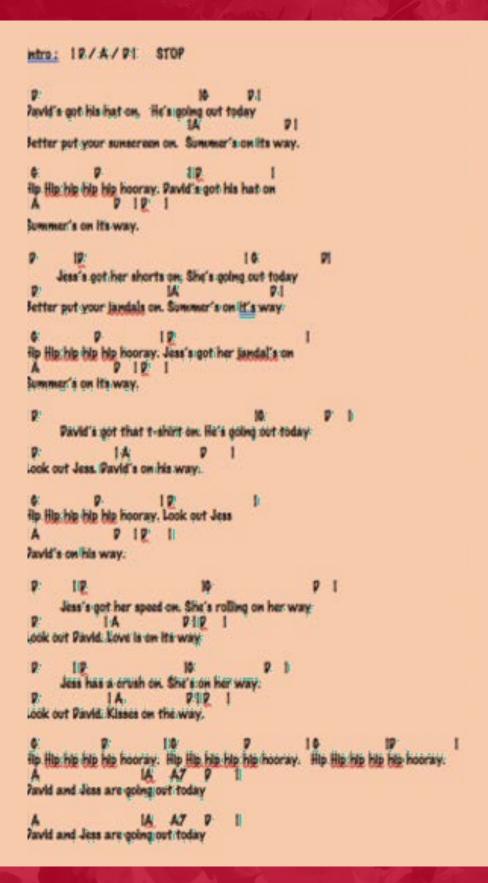
We don't jump fences any more We walk through our own gate



Cover Art:

Figure 23. Lyrics to a song have been placed overlap an image of an acoustic guitar. Half of the guitar is covered. The song is to be played in the key of D with chord changes written between the lyric lines.

"Davids got his hat on"

Tune: "The sun has got its hat on:" Noel Gay & Ralph Butler (1932)

Lyric: Jess Kittay

We don't jump fences anymore. We walk through our front gate

We do almost everything together

David and I have been married for three years now.

Well it will be four this March Jess

We do almost everything together. It's how we are, so we want to tell our story - together.

That way it will be right.

The sun has got its hat on (intro)

David and I first met at a day programme. When David first started, he sat on his own. He didn't have anyone to talk to, so I went up and asked him if he was ok.

Jess coming up was a bit of a shock.

Not a lot of people would talk to me because I was different. I stand out in a crowd.

But Jess came over, and that is where it all started.

David was the first man who really talked to me. Literally from the first time we sat down.

Jess sat and had lunch with me and I asked her how things were for her. Jess told me that she was not really liking where she was living. I told her I had the same problem where I live. I know what you are going through.

There was a sadness in David's life, so what I did was write down how I was feeling about him.

It was the first song I ever wrote.

At that point we had been going out for months but I wasn't allowed near David. My caregiver helped me get to get all the words written out. I rang David before I did.

And what did I say Jess? I didn't have a problem with it. So long as there are no dodgy words.

The troubles

Getting to know David was a slow process.

We took the relationship slow didn't we. For about three years we took it slow.

If Jess wanted time we just gave it a miss, you know. We didn't commit to any long term relationship until we knew it was right, did we? For a long time we had monthly visits and I wasn't allowed to take Jess to the movies or anything like that.

The day after I met David, I asked him out. But staff stopped it. They were telling me I wasn't allowed this.

I knew people would be telling you "Oh David is not who you think he is - because of the trouble I got into when I was younger." I knew people would be telling you it was a mistake.

But what mistake Jess? You haven't made a wrong mistake at all.

And I said, what's to be careful with. If I don't talk to him, I won't learn what life is about.

He can tell me. He has a voice.

We had our first date on the 29th of April, 2011. We went to a cafe. Jess was 23 and I had just turned 19.

The next time I phoned to see if it was ok for me and Jess to go out they said no because you've got charges. What had happened was a staff member at the house I was living in rang and told Jess's staff I had a conviction. Everyone assumed I had been charged. Because I had a disability they thought I wasn't going to be honest.

I've been hurt basically all of my life because of it. I wasn't allowed to marry Jess and at the start I wasn't even allowed to see her.

Jumping fences

They couldn't stop us all the time. Sometimes I'd run away.

I would often storm off. You know, because I was getting bullied at the house.

I used to sneak off other times too. When staff went down to the wash-house I would sneak outside and book the mobility van so they didn't know where I was.

And then she would ring me and and say is it all right for me to come in? We spoke to my staff and they decided yep ok, we'll give it a chance.

The taxi drivers knew more about what we were doing.

That's why we get respected as a well known couple.

We would meet secretly at the club too. I started going to be with Jess until one of Jess's staff popped in and put in a complaint and I was stopped from going. In the end I was allowed to go, but Jess always had to bring a staff person.

The sun has got it's hat on (reprise)

When David started coming I was a bit nervous. I used to have this staff person following me everywhere – like a little puppy.

People didn't come up to me to say hello. I'm just sitting there thinking I'm looking like a piece of trash really. Eventually I turned around and said This can't go on.

I think the other members saw Jess as a very lonely person. When I started going things started to change. I was her boyfriend, not her staff.

My staff were really there to make sure I didn't have any contact with David. That's where the song comes in.

I was there that night. When Jess sung it. Jess was crying and I wasn't allowed to go near her.

I couldn't go up to her and say You did a good job. I wasn't allowed to say, Well that sounded beautiful darling.

The song is about discrimination. People don't have the right to say who you can see. If you were in a relationship with someone, what would you do? If you loved the person, what would you do? Sit there and watch them get discriminated against. I wanted to be with David, so I sang it out over the top of the other members. I sang it to David and I sang it to the support person. David and Jess are going out today.

This man who keeps on coming and fighting for us to be together.

David and Jess are going out today.

Maybe this is the way it's gonna be for yous

I was a bit of a mess back then. I would ring David because he would listen.

I remember ringing quite a lot of times crying.

One day I spoke to one of David's staff members about it all. She was the first person to say, We might be able to make this work. You have turned David's life around.

This crap was constantly going on. So in the end I decided to go to the Needs Assessment Service and say, enough is enough.

I had it all on my laptop. When Jess was talking on the phone to to me I would write it down. In the end I printed it off and took it into the needs assessment service.

I said to them, Hi I am David Austin. I am advocating on behalf of Jess Kittay. And that's where it all came out. Jess gave me her mothers number and I rang her. She told me she knew Jess wasn't happy with the way she was being treated and I said no, neither am and that I had gone to the Needs Assessment because I was concerned.

Her rights were not being respected!

In the end Jess's mum said maybe we need to look at having a sleepover at my place and rang my co-ordinator. That's what happened. The next day and my co-ordinator says, Would you feel comfortable going and spending a couple of nights with Jess and her mum?

I remember lying on mums spare bed... and I said to David, I never want to go back to that shithole.

We were only there for one night...... but It was enough. Enough for Jess to decide we wanna keep this up. So we did another trial. My co-ordinator asked me how it worked.

I thought it went really well. I told her, I can't see what the concern is and she goes, Oh well, maybe this is the way it's gonna be for yous.

Please don't get shocked

Don't take this the wrong way Jess. I was pleased I managed to get you out of there.

I thought no one was going to listen to me.

Were you worried?

Well other people were. They didn't want to see me get used as an advantage to look after you all the time. People would tell me it's hard to look after someone with a physical disability.

They said it would be way too hard for me.

People didn't have a lot of faith in either of us did they?

Jess's disability is not really anything to be worried about and it didn't take us long to figure that out.

The only thing that did worry me was when you told me you had been sexually assaulted. I did go to my staff and say, well what do I do? You know what do I do If she well, wants somethingor whatever. I'm not going to say because I don't want to embarass Jess.

The topic for her will be a bit awkward.

(Laughs) No!

We don't really talk about that kind of stuff.

For a start I was a bit scared.

I never imagined I could live in my own house. When I'm in bed, I stay in bed. I can't get out.

If there is a strange noise I have to rely on someone else figuring out what the noise is.

David changed everything.

Please don't get shocked, but I was sexually assaulted when I was twelve.

I had a caregiver who used to bring her boyfriend around. They were visiting and he touched me around my ribcage and tried to undo my buttons while I was on the couch. I ran to my bedroom. I shut my curtains, that's how fucking scared I was.

Sorry for swearing.

I didn't know what to do. I didn't know what to say to mum. I do remember telling her to get him out of here.

It was six months before I went to the cops.

I asked mum if she could come because it was her friend.

They just smacked him on the hand.

They didn't do nothing.

They didn't do diddly squat. He had to do it to someone else first.

Because of that I was frightened of men. I never thought I was going to be married or anything like that. I thought that won't work.

Sometimes I have flashbacks.

Then you have to sit up, don't you?

I have to sit on the end of the bed. I have to do what I have to do.

I was twelve.

Do you reckon I'm the one?

People were shocked when we got engaged weren't they Jess.

My father was quite shocked. My stepmum was quite shocked. My brother was quite shocked. My little brother was quite excited.

People were actually quite nasty. In the end we got engaged to shut everybody up.

At the time we didn't know anyone with a learning disability who was married. I don't really know why people with a learning disability don't marry.

Well I think anybody with a disability can be married to who they want, when they want. Other people shouldn't have that control. We really didn't think it was so unusual.

To us it was just a normal thing to do.

Well you might not have been thinking about it too much, but I had!

I asked David three times. I asked him. Do you think I am the one?

Do you reckon I'm the one for you?

I won't ever get this chance again

The first time we had been intimate was when I fell asleep on David.

I was around at Jess's and she was upset. You know, pissed off at what was happening and so I picked her up and put her on my knee and she just relaxed and ended up going off to sleep.

He was talking to me and then I didn't respond.

Basically David has soft skin. He's got very, very, soft skin. I don't know why I fell asleep on him. It was just the touch. The touch of his hand on my stomach and stuff.

So here I was, sitting there talking to her and the next thing I looked and her eyes were closed and I thought Oh fuck! Anyway, Jess's staff knock and I give Jess a wee tickle on her hip. Woke her up. Put her back in her wheelchair. Did her up because I didn't want to get caught with them walking in and seeing Jess on my knee.

(Laughs). Yeah we had to be very secret. Very, very, very secret.

They didn't aknowledge the way we were. We couldn't talk about it.

They would have stopped it alright!

I didn't trust anyone. Especially the service.

We couldn't really have sex. So we just cuddled and stuff like that.

We weren't too sure about it at the start were we. But it all turned around and became ok.

We took it slow, then all of a sudden, yep Jess started wanting me to touch her and that was fine. I didn't have a problem with it.

I took control because I wasn't too sure how to....

How to ask me?

Yes to ask you. So I wrote it down in a letter and got David to read it out.

We had no opportunity to talk about sex so writing a letter was the only way I could think of to let David know.

Sex is a little complicated for me too. We have to do things differently, so I had to find a way to let David know what I wanted.

I didn't know what to think of that did I. To be honest I was a bit hurt.

I had to ask my staff if it was normal. Putting it in a letter like that.

No! You didn't know what to think of that. (Laughs). So I explained it again.

It was also a pretty big step for me. Because of me being abused.

So that's when we leave it.

And at other times I do feel like it. Depending what my mood is.

Sex helps. My muscles get tight. Sex helps me to relax.

Touching me like that also replaces a bad feeling with a good one.

I'm fine with whatever Jess wants to do. I don't want to force things on to her that she doesn't want, you know.

It's her decision at the end of the day. I don't make decisions for her.

Well come on what about you?

Well it doesn't really happen for me that way. I don't really have needs that way.

It was really hard for me to touch Jess at the start.

I didn't want to physically touch her because if someone saw me doing something to someone else, I worried about getting reported to the police.

Because I've had that history I was a bit against it.

And I said, it's your choice if you don't want to touch me. At that stage I was really, really, really wanting to be intimate though.

Which is what ended up happening.

If I ever ended up going to prison, Jess ends up back in care and that's the relationship over.

I won't ever get this chance again.

They had to state their concerns I guess, didn't they?

When we started living together we didn't know too much about sex did we?

At the all boys school I didn't have many friends. You know, being different.

Well I can remember going home one day and showing mum I had four NCEA credits in sex education!

I remember thinking, how can a disability person pass this test when she hadn't had it?

I had that as well, but I failed!

I absolutely passed with flying colours.

Sorry if this sounds wrong. I had to put a condom on a stick.

I was quite angry. I turned around to my teacher aide at that time and said, "Do you actually have any faith in me passing this?"

And what did she say?

She goes, No.

And I go, well, how can I learn when I don't try these things? How can a person pass with flying colours when you're telling me I couldn't have anyone to do it with?

It's important for everyone to know that people with a learning disability want a partner.

And want to know more about how to be intimate with them.

Pretty much the only place I talked about sex was in the counselling up at the hospital.

They only told be what I wasn't allowed to do.

I always felt as if they were watcing what I said.

You know to decide if I was a bad person.

I went up to the hospital too. I was doing walking, cooking and sexual reality.

Sexual reality was about having a relationship and what the kids would turn out like if we were to have kids. They had to state their concerns I guess, didn't they?

It wouldn't matter if the child had a disability or not

We did talk about having kids

I looked into it properly because I didn't know if I was allowed to.

So I went to Family Planning. They said with my disability possibly not.

They weren't that helpful really. They gave me condoms and god knows what else but I thought to myself, Why aren't you listening?

I went to a male doctor after that and he said you can try but it would have to be delivered early. So we just kind of gave up.

It's a shame we can't have kids because your foster parents said....

I'd make a good father.

We thought may be we'd adopt a child. That way I don't pass my genes and there's is a chance with Jess's disability too.

So we thought maybe adopting would be the safest. Or fostering.

It wouldn't matter if the child had a disability or not. It wouldn't make it harder for us.

If the child had a physical disability, it wouldn't really matter.

I know what to do and Jess would be its mum.

Because we can't have kids ourselves we put a lot of energy into our family.

The sun has got it's hat on (coda)

Do you know, even after I married David, people would still come up to me and say, You won't last. And I would tell them Just watch this space! You just watch me jump this fence.

In the end we proved them all wrong.

And we still prove them wrong.

We are still proving people wrong aren't we.

I knew I was able to have a flat on my own. And have a proper relationship.

There was so much negative stuff about us.

If I hadn't met you David, I wouldn't be here today.

How do you mean sweetheart?

Well because you were my advocacy person.

If David was gone, I would have taken my life. That's how I feel.

And if someone was to take David away from me, well what am I supposed to do?

But Jess that's never gonna happen.

Jess helped turn my life around. When you first got with me I was very unsure.

Because of what history I had. I just wasn't sure if a relationship was going to be my thing. But then I thought Jess is worth the risk.

And that's the way it's been. We do things together.

We knew who we were.

In a way that's the point of our song.

When we are allowed to be together and to decide things for ourselves, the future looks brighter.

The sun has got it's hat on. Summer's on its way!"

I do think there is still a lot to be proved, right, but I don't think there's anything major for us to prove anymore.

We have done what we can now.

I don't think there are fences we need to jump now.

In the future we will just walk through our own front gate.

Key Messages

People with a learning disability always feel like they have to prove something to get something. I don't think that's having the same rights as everyone else

- We noticed how David and Jess always felt they had to prove something just to have or do something. They had to prove a lot!
- Having an intimate relationship feels like the end of a very long ladder. You have to prove that you can do all the lower rungs before you can get there. Disability support services (and others) never assume it's your right to start at the top of the ladder.
- Whether you have a disability or not you have the right to an intimate relationship. You shouldn't have to have a relationship just to prove to other people you can do it. We are no different to anybody else except that we have to work so much harder to be together.
- We did think that other people always saying "no" might have motivated David and Jess to give it a go though

Disability Services control our relationships

• It is not right that people who work in a service can tell you who you can see and who you can't. It's our choice. Unless the person has asked you to be an advocate staff have no right to step in.

Disability support services limit the possibilities of relationship by what they do say and do

- Community Group Homes are not spaces to be in a relationship with someone.
 Friendships are always scrutinised and there is no privacy. You always have to sneak away. You have to escape your service to be in a relationship.
- People with a learning disability are often told they are not allowed to have sex in their service. It's a policy. Couples who are caught doing it can get in big trouble.
- When you are not allowed to have sex in your service there is no proper place. You have to do it in places like the park.
- It is like Big Brother is always watching you.

Just as importantly, disability support services limit the possibilities of relationship by what they do not say or do

 Partner relationships are open and they are equal and you care about each other equally. We think that relationships with a partner are what makes the biggest difference in people's lives. They are really important and should be respected and valued by those whose role it is to support us.

- Relationships take time. You have to build loving relationships by learning how you connect and what you enjoy doing together. We think it is critical that services talk about and provide people with a learning disability the chance to build intimate, trusting and loving relationships by supporting (not surprising) life sharing.
- Relationships are built one-to-one, not one-to-five.
- People who live in disability support services are not often supported to build relationships by doing things non-disabled adults do to become intimate, like out to a restaurant or planned a date. We also think;
- People with a learning disability have fewer opportunities to meet people and become intimate, which means you get no chance to know people in a way that would help you decide if you want to be in a deeper relationship.
- Sex feels like the needle in the hay stack. A precious and hard thing to find surrounded by the "hay" of everyday living. People with a learning disability who spend a lot of time in disability support services are steered towards non-sexual lives by the "hay" of being taken to places and kept busy doing things where meeting someone and becoming intimate are not easily possible.
- People with a learning disability never get any practice or to feel confident taking things beyond friendship.
- Not encouraging people to think of themselves in sexual can lead people with a learning disability to doubt that they have the same rights as others. You ask yourself is it ok to go through the gate (of friendship). And exactly what do you do when you get to the other side of the gate.
- We would like to hear that it is normal and natural to have sex and want to be sexual. You need to have trust and faith in yourself to become a caring and responsive lover. Not being able to talk to people as if sex was a real possibility takes away the trust and faith we think you need in yourself.
- We would like to talk about how to have sex. But only with people who are open, and listen properly and accept that we would like to have sex.
- When people with a learning disability talk to staff it often feels like there is a right (approved of) answer. We feel the lack of opportunities to talk openly and honestly harms people with a learning disability because we are more likely to be met by more issues and opinions (discrimination) than people who do not have the label of intellectual disability.

- People with a learning disability don't talk to other people with a learning disability about sex or sexuality either. We think this is because when you are not used to hearing those kinds of conversations you don't know if it is ok to talk about. "Not talking (or hearing) about it makes sex a more complicated thing to talk about.
- We also feel that believing you didn't have the right words (vocabularies) makes it much harder for us to know what to say too.

Sex Education

- We think the way David's experienced sex education was more about what he couldn't do in a relationship. People with a learning disability are told "no you can't" all the time.
- The messages people with a learning disability hear about sex are almost always negative.
- o Don't get caught
- o You have to be careful of people who are paedophiles or want to take advantage of you
- o Women with a learning disability often get sexually assaulted by men
- o People can watch or record you on their phones
- o You need to have safe sex
- o You can't get people pregnant
- o You can't have children
- o You can't have sex until you have a good income
- We also think men with a learning disability find even getting into the partner zone frightening because of the all the negative messages about male abuse.
- On the other hand, sex education for people with a learning disability almost never includes conversations about sex being pleasurable or a way of showing your partner you love them. Sex as part of loving someone is never talked about. We are never told positive stories about sex.
- (Thank goodness for story-telling).

What we know is that many people with a learning disability take it slow

 People with a learning disability are prepared to take the time to build a connection slowly. David and Jess took four years to get engaged and both said they took everything slowly. We think that this is the more usual way that people with a learning disability build relationships. We think that people with a learning disability tend to take it slowly because they wait until they know they can trust the other person. To a person with a learning disability, trust is one of the most important things in life.

One of the other things you can't do is have children

- We think that one of the ways that families and disability support services don't trust women with a learning disability is by putting them on the pill without asking or talking to them.
- Being on the pill just means that women with a learning disability can't have children It doesn't always mean you can have sex. You still can't do that!
- We do know women with a learning disability who have made the decision not to use contraception because it should be a woman's choice. No one else should make that decision for women. Having control over who and when you are in a relationship means that women can be confident their decision is the right one.
- We noticed that Jess and David had looked into becoming parents. We didn't know anyone with a learning disability who was bringing up their son or daughter in our community. We think that that could also be because of the negative messages that people with a learning disability hear about parenting too like;
 - o There are lots of rules about bringing up children
 - o Being a parent will take up all of your time
 - o Being a parent will take up all of your money
 - o That you don't have enough room in your place to be a parent
 - o Being a parent is too much of a responsibility for you
 - o Children are a burden
 - o You need to be able to drive a car
 - o You will have your children taken off you
- We did notice that David's foster parents said to him that he would make a good dad though. We were surprised because we have never heard anyone say people with a learning disability have something special and important to give their children or that being a parent can be the most important thing you do in your life.
- We remembered having dreams about having kids when we were younger and wondered if all of the negative messages about parenting had changed our dreams. We think we just assumed it wasn't possible because we had come to believe that that is the way life is. People with a learning disability aren't allowed to be parents.

They got engaged to shut everyone up!

- David and Jess said they got engaged to shut everybody up! We wondered whether anyone had said congratulations? That's what most people would say if you told them you were going to get married.
- When no-one expects people with a learning disability to get married we learn not to expect it for ourselves. The first time I heard someone with a learning disability was married it blew my head off. I just didn't think of it as an option.
- Like becoming a parent, we think we dreamed about getting married but then forgot about it.
- Talking more openly and honestly about sex and marriage and may be becoming
 a parent might help us to reimagine the future David and Jess's story gave us this
 chance.

What do you think?