1

00:00:03,560 --> 00:00:06,000

The reason I wanted to go into my community

2

00:00:06,000 --> 00:00:09,760

and help other families is because I knew if I suffered

3

00:00:09,760 --> 00:00:12,080

in silence for so many years, there’s others out there

4

00:00:12,080 --> 00:00:13,920

doing the same.

5

00:00:13,920 --> 00:00:16,440

Gandhi said it best, “be the change

6

00:00:16,440 --> 00:00:18,880

you want to see in the world”.

7

00:00:18,880 --> 00:00:19,720

So that was me.

8

00:00:19,720 --> 00:00:22,440

I said, I'm going to take this on because something

9

00:00:22,440 --> 00:00:24,920

needs to change.

10

00:00:24,920 --> 00:00:26,600

And our families need to know they don't

11

00:00:26,600 --> 00:00:28,320

have to hide away anymore.

12

00:00:28,320 --> 00:00:30,960

My name is Kathleen Sanft,

13

00:00:30,960 --> 00:00:35,000

and I’m from, born in Rawene in the Hokianga

14

00:00:35,000 --> 00:00:38,280

and I live here in the beautiful Eastern Bay

15

00:00:38,280 --> 00:00:40,200

in a small town called Ōpōtiki.

16

00:00:42,320 --> 00:00:49,080

We had two children diagnosed with moderate to severe autism,

17

00:00:49,080 --> 00:00:53,120

as well as global developmental delay

18

00:00:53,120 --> 00:00:56,280

and other such learning difficulties.

19

00:00:56,280 --> 00:00:58,920

And I didn't know how to cope.

20

00:00:58,920 --> 00:01:05,760

So I didn't do the best thing in hindsight now.

21

00:01:05,760 --> 00:01:10,160

I medicated with drugs and alcohol when I didn't

22

00:01:10,160 --> 00:01:13,160

have the kids because I didn't know there

23

00:01:13,160 --> 00:01:14,520

was anything else.

24

00:01:15,120 --> 00:01:18,440

Living in a rural community didn't help.

25

00:01:18,440 --> 00:01:23,880

We love it as a little fishbowl, but in the beginning that little

26

00:01:23,880 --> 00:01:26,400

fishbowl couldn't help us.

27

00:01:28,000 --> 00:01:30,600

My darkest moment was ringing my parents and saying,

28

00:01:30,600 --> 00:01:32,880

I need to drop her off because I feel like driving

29

00:01:32,880 --> 00:01:35,080

over the bridge with her.

30

00:01:35,080 --> 00:01:38,080

Because I didn't know what I was doing and I didn't know

31

00:01:38,080 --> 00:01:40,280

how to calm her.

32

00:01:40,280 --> 00:01:44,040

All the checklists in the world don't prepare you for that

33

00:01:44,040 --> 00:01:45,120

sort of thing.

34

00:01:47,400 --> 00:01:50,280

Are you going to pass it to your sister?

35

00:01:50,280 --> 00:01:53,960

Ready and go.

36

00:01:53,960 --> 00:01:55,960

Good job!

37

00:01:56,640 --> 00:01:59,440

In the early days, in the dark days, someone must have told

38

00:01:59,440 --> 00:02:01,680

Parent to Parent that I wasn't coping.

39

00:02:01,680 --> 00:02:04,920

And one of the ladies there rang me and offered me

40

00:02:04,920 --> 00:02:07,640

to go on a mum's getaway.

41

00:02:07,640 --> 00:02:10,640

Shared a lot of tears and memories and tips

42

00:02:10,640 --> 00:02:15,680

and parenting hacks and coping strategies.

43

00:02:15,680 --> 00:02:17,480

I thought that was awesome.

44

00:02:17,480 --> 00:02:19,160

That was what I needed.

45

00:02:19,160 --> 00:02:21,440

Someone else knew what I needed without me

46

00:02:21,440 --> 00:02:22,400

having to say it.

47

00:02:23,800 --> 00:02:26,520

So Parent to Parent is an information service.

48

00:02:26,520 --> 00:02:28,600

It is for the parents and the siblings.

49

00:02:28,600 --> 00:02:31,600

And if we can make a strong scaffolding for the family,

50

00:02:31,600 --> 00:02:33,800

then the disabled or neurodiverse child will have

51

00:02:33,800 --> 00:02:34,520

a better life.

52

00:02:34,520 --> 00:02:38,680

And Parent to Parent is about connecting parents with parents

53

00:02:38,680 --> 00:02:41,680

and together hanging out with people that understand, that walk

54

00:02:41,680 --> 00:02:45,720

the same life and just get it.

55

00:02:45,720 --> 00:02:50,600

We were asked, would we like to go with a self-directed

56

00:02:50,600 --> 00:02:51,960

funding host?

57

00:02:51,960 --> 00:02:54,080

So we went with Manawanui.

58

00:02:54,560 --> 00:02:58,920

It made me feel empowered that I have the choice.

59

00:02:58,920 --> 00:03:03,360

This is the therapy, this is the benefit, and this is hopefully

60

00:03:03,360 --> 00:03:04,320

the outcome.

61

00:03:04,320 --> 00:03:07,280

That's what fit our family the best.

62

00:03:07,280 --> 00:03:11,280

My first impression of Kathleen was that she is a great mum.

63

00:03:11,280 --> 00:03:13,280

Yeah, she is a great mum and she's always

64

00:03:13,280 --> 00:03:14,600

put her kids first.

65

00:03:14,600 --> 00:03:17,600

So yeah, I really love the model of self-direction.

66

00:03:17,600 --> 00:03:19,040

It helps my kids.

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00:03:19,040 --> 00:03:21,760

My kids have support, but the run off effect is that

68

00:03:21,760 --> 00:03:23,840

I'm not so stressed, I have more time,

69

00:03:23,840 --> 00:03:28,280

I have more patience, and the kids get the best

70

00:03:28,280 --> 00:03:29,320

version of me.

71

00:03:29,320 --> 00:03:32,320

Personal budgets are really good because it's based on the child's

72

00:03:32,320 --> 00:03:36,760

needs or the individual needs, not on what my needs are or what

73

00:03:36,760 --> 00:03:39,000

your needs are or anyone else's needs.

74

00:03:39,000 --> 00:03:42,000

So they're not limited by, it’s all about that

75

00:03:42,000 --> 00:03:44,200

individual person.

76

00:03:44,200 --> 00:03:47,680

We started a support group here in Ōpōtiki and we’re called

77

00:03:47,680 --> 00:03:49,000

Whānau Awhi.

78

00:03:49,000 --> 00:03:53,960

We have a committee of 6 or 7 members and they're all

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00:03:53,960 --> 00:03:55,680

mums of autism too.

80

00:03:55,680 --> 00:03:58,680

So not only are we supporting these families,

81

00:03:58,680 --> 00:04:00,120

but we're getting the ideas direct

82

00:04:00,120 --> 00:04:01,800

from these families.

83

00:04:01,800 --> 00:04:04,320

And when we hold events, we don't discriminate,

84

00:04:04,320 --> 00:04:06,160

we don't take the diagnosed child

85

00:04:06,160 --> 00:04:07,880

and one carer.

86

00:04:07,880 --> 00:04:09,240

We take the whole whānau.

87

00:04:09,240 --> 00:04:13,120

We just see what the barriers are and break it down and then we

88

00:04:13,120 --> 00:04:15,080

just pump it out one step at a time.

89

00:04:16,160 --> 00:04:19,720

That environment of that camp away from home

90

00:04:19,720 --> 00:04:22,720

gives us time to breathe, reflect,

91

00:04:22,720 --> 00:04:24,640

take in others’ experiences.

92

00:04:24,640 --> 00:04:28,120

My hope behind it is that someone sees this somewhere in the

93

00:04:28,120 --> 00:04:31,680

system and they see that this is a model that needs to be rolled

94

00:04:31,680 --> 00:04:33,760

out regularly.

95

00:04:33,760 --> 00:04:36,760

Down in Ōpōtiki, Whānau Awhi has amazing stats where

96

00:04:36,760 --> 00:04:39,760

80% of the families are together and that shows

97

00:04:39,760 --> 00:04:42,200

they've got strength within each other.

98

00:04:42,200 --> 00:04:45,320

We see this as such a template for our families

99

00:04:45,320 --> 00:04:48,680

and we're really excited about bringing it to our little

100

00:04:48,680 --> 00:04:51,680

rural communities and seeing Whānau Awhi roll out right

101

00:04:51,680 --> 00:04:53,200

over the country.

102

00:04:57,400 --> 00:05:00,880

Today is the first Ōpōtiki Kids Market.

103

00:05:00,880 --> 00:05:03,120

All these stores are made by kids being supported

104

00:05:03,120 --> 00:05:08,160

by their families trying to give them another

105

00:05:08,160 --> 00:05:10,520

pathway in life.

106

00:05:11,080 --> 00:05:14,080

My hopes for my children is that our daughter does have that

107

00:05:14,080 --> 00:05:17,680

business established when she's older and she's got her two

108

00:05:17,680 --> 00:05:22,720

brothers packing and picking orders so that they can fully support

109

00:05:22,720 --> 00:05:24,480

themselves financially.

110

00:05:24,480 --> 00:05:26,440

My job as a parent, I need to provide

111

00:05:26,440 --> 00:05:28,000

them a home.

112

00:05:28,000 --> 00:05:32,640

So that when it’s time for me to tap out, they’re not going to be

113

00:05:32,640 --> 00:05:37,400

consumed by the system and their support services can come and

114

00:05:37,400 --> 00:05:41,680

go, but that is enabling a good life for them.

115

00:05:41,680 --> 00:05:44,680

I’ve just got to do my job to meet that standard.

116

00:05:44,680 --> 00:05:47,160

I see where I need to be.

117

00:05:47,160 --> 00:05:52,360

It's a lot of steps to get there, but I'll do it.