**Young Carers in Fife consultation and outcomes – July 2018**

Introduction

A consultation was completed with young carers in Fife from April 2018 until June 2018. Focus group discussions were used in secondary schools and activity session in primary schools. An online survey was also compiled and offered to young people via school and our third sector partners. Consultation was initiated at the Fife Young Carers focus group where they were asked about services and the support being offered. The group also commenced the review of the current young carer strategy. The consultation was then formally launched via the weekly news bulletin to all head teachers and support for learning teachers in May 2018. There was also general information compiled via the education pupil wise survey 2017-2018. This information was analysed and added to the outcomes of this consultation. The main consultation was completed in two parts:

1. Focus groups offered and completed across Fife schools
2. Online Survey offered to young carers across Fife

Method

The focus group information was transcribed and analysed using a grounded theory approach, which involves grouping similar data together into categories until common themes emerge. The statistical information was analysed using electronic system compatible with the online survey and converted into visual graphs. Conclusions were drawn based on both sets of data. Full written and verbal consent to participate and share this information was obtained from young carers, parents and guardians as appropriate.

134 young carers in total participated in the consultation. 102 young people participated in the online survey. Ages ranged from 12 to 18 years old with a small proportion being under 12 years. 32 young people participated in the focus groups with age range of 10 years to 17 years old. Young carers were represented from across Fife. Young adult carers were also represented in the survey making up 27% of the survey population.

**Online Survey**

1. What is important to Young Carers?

All of the areas noted from the initial young carers focus group discussion were important to young people however receiving support with their caring role was rated as most important at 85% (including practical support from other family members and emotional support of having someone to talk to) receiving information was rated second most important at 83% with having a break from caring, time with friends and access to leisure activities were rated collectively at 80 %. Access to schoolwork (including time to do homework, study and access classes) was least important at 76 %. This information supports the topics that emerged via the focus group discussions however there was more discussion regarding accessing schoolwork in the focus groups and it was highlighted as important. Access to schoolwork forms part of the theme – making connections. (see graph 1)

Graph 1

1. Benefits of caring

Young carers in Fife highlighted that there are many benefits to looking after someone at home. The main benefit was that it helped them be more responsible. 87% rated this as the main benefit of caring. 74% reported it helped them be more organised and 68% felt it was rewarding to care. Only 49% felt it helped with their confidence. This information also supports the themes that emerged during the focus groups with sense of responsibility being a consistent topic and forming the theme – sharing responsibility. Many young people emphasised that they took great pride in their caring role and felt they were the best person to provide that care because they knew the persons needs so well. (see graph 2)

Graph 2

1. Impact of your caring role.

The most significant impact highlighted during the survey was young people feeling tired and worried. 61% reported feeling this way. Some of the quality information from focus groups also highlighted this with young people’s own mental health being a consistent theme. Often feelings of worry led to their own issues with anxiety. 51% reported that they felt it affected their ability to complete their school work. It was not felt to impact as much on time with friends (44%) and feelings of isolation and loneliness were rated lower (41%) however this differed from the focus group discussion where time with friends and difficulty meeting friends were discussed consistently. Time with my friends’ forms part of the theme – balancing time. (see graph 3)

Graph 3

1. What support would be helpful?

Knowing what to do in an emergency was rated by young people as being most helpful with 82% stating information on this would help them with their caring role. School staff having an understanding of the caring role was also rated highly with 77% stating this would be helpful. Practical training and advice were also reported to be helpful (73%). Breaks from caring (71%) and having someone to talk to (70%) were rated slightly lower. Information via the focus groups rated speaking to someone as most helpful and highlighted that talking to someone was a good source of support. This forms part of the theme - making connections. (see graph 4)

Graph 4

1. Types of disabilities/difficulties of cared for person.

The conditions and illnesses varied across the survey but the most common condition affecting the cared for person was a physical disability at 68%. Supporting people with their mental health was also common with 43% young people providing care in this situation. Supporting someone with a learning disability was rated as third most common with 28% of survey population providing care to this group. Autism, diabetes and incurable cancer were also highlighted under the ‘other’ category. This shows the variety and range of disabilities and illness that young carers are dealing with. (see graph 5)

Graph 5

1. The person you care for.

Young carers completing the survey provided a range of support to different family members. A parent is most commonly supported with 55% of survey population indicating this. 31% of young carers are also currently support their siblings. It is worth noting that 10% of young carers in the survey cared for more than one member of the family, for example a parent and sibling or grandparent. This was also highlighted via the focus group with several people providing care to different family members. This means their caring role is complex and involves providing different types of care. For example, caring for a disabled sibling whilst providing emotional support to a parent. (See graph 6)

Graph 6

1. Help you access at the moment.

Authorisations cards proved most popular with 66% of young people using them. Free travel and leisure passes were also being used regularly with 64% young people accessing this support and highlighted it was very useful, especially in more rural areas. 63% of young people talk to other young carers as a form of support and 50% have accessed the ‘time for me’ fund. Both of these supports were a recurring topic during the focus groups discussions with 12 young people making reference to how helpful it is to meet with and talk to other young carers. ‘Time for me’ fund was also discussed with children giving examples of how this had helped them cope with their caring role. (see graph 7)

Graph 7

1. Do you have any ideas about how we can improve services to young carer's?

Ideas from the online survey and focus groups have been combined. Due to the volume of answers from these open questions, answers were put into similar categories and priorities identified:

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| --- | --- |
| Ideas | Priority |
| * More free travel * Help to learn to drive | Help to get around |
| * Services to support my mental health * Continue to raise awareness and reduce stigma | Emotional health |
| * Support post school and into adult hood * Keep in touch with young adult carers * Offering something else for person I care for if they don’t meet criteria * More calls and check ins if not attending group * More help around exam time * Help with planning after High school | Support into adulthood |
| * Activities to learn more skills * Breaks from caring to have fun * Breaks with our peers * Trips and activity days * More clubs for disabled siblings * More care for siblings/parents | Give me a break |
| * Sharing ideas with other young carers * More groups * y.c groups in schools * Employ young adult carer to support other young carers * Give charities more support so they can help more people * More support for younger children * More awareness raising for everyone * 1:1 school workers, transition workers | More of what works |

1. Do you have any additional comments you would like to tell us about?

|  |  |
| --- | --- |
| Comments | Priority |
| * Time for me takes too long * Didn’t really enjoy FYC – did not like talking or doing activities I was not good at * Mix with more y.c’s my age | Make things work better |
| * Teachers and school understanding if we miss things it is not our fault * Listen to y.c and help them, don’t wait until they are so low, they are suicidal | Increase understanding and action |
| * More groups please * Respite from FYC really helps * Advice on practical things * Going on trips helps * More funding to help more y.c’s * More support in primary school * Teachers to have more understanding | More of what works |

**Focus Groups**

Seven schools offered to take part in the focus groups and involved 32 young people.

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| --- | --- |
| **Schools involved** | **Area of Fife** |
| Woodmill High School | West |
| Bellbaxter High School | North East |
| Auchmuty High School | East |
| Kirkcaldy High School | East Central |
| St Andrews High School | East Central |
| Newburgh Primary School | North East Fife |
| Southwood Primary School | East |

Findings

The following information came from the discussions that were based on five open questions.

1. What is important to you in relation to your caring role?

2 .What information and advice would help?

3. What would make a difference in supporting you?

4. What would help you achieve time for yourself?

5. Do you have any ideas on how we can improve things?

From this information categories emerged that were later combined to reflect five main themes: These themes have been converted into outcomes in relation to the young carers strategy and will form the basis for the updated strategy and action plan.

|  |  |
| --- | --- |
| Categories | Themes |
| Feeling responsible  Sharing the load  Being ‘on call’ | Sharing responsibility |
| Support  Connecting with others  Someone to talk to  Accessing communities | Making connections |
| Balance caring  Time for self  Breaks from care  Time to be a child  Help during holidays | Balancing Time |
| Knowledge and understanding  Just keep me updated  Being a part of something  Keep me informed | Being involved |
| Mental health  Identifying with role  Dealing with emotions  My well being  Hardship | Emotional wellbeing |

**Pupilwise survey 2017 -18**

Pupils were asked if they regularly look after a family member who has an illness or disability (including someone who has a drug or alcohol problem.) 23,440 children and young people completed the online survey with 6,785 identifying themselves as young carers. This number can be broken down further with 4,856 pupils identifying themselves as young carers within p4 – p7 and 1,929 identifying themselves as a young carers within secondary school. Pupils were asked to rate education’s performance in relation to supporting them with their health and wellbeing. Under each SHANARRI indictor young carer’s rated this in line with their peer group, which was mostly positive, for example:

SAFE/NURTURED: 80% of young carers in Fife reported they knew who to talk to in school if they were upset or worried

HEALTHY/ ACTIVE: 73% of young carers reported that school is helping them to become more resilient and able to cope with challenges

RESPECTED/INCLUDED: 70% of young carers report that staff listen and pay attention to what they are saying

These results support the consultation feedback around how important it is to have someone to talk to about their caring role and the need for understanding from others. However some areas were rated lower by young carers. This was also in line with their peer group for example:

ACHIEVING/ RESPONSIBLE: 36% if young carers reported that their school knows what I like doing when I am not in school

TRANSITIONS: 49% of young carers reported school has helped me prepare for the world of work

This information supports what young carers report via the consultation, specifically around support with transitions into adulthood and the need for staff having an understanding about their caring role at home.

Overall the pupilwise survey highlighted similar themes that were rated as important during our recent consultation. For example, the strengths from the pupilwise survey relates to outcomes around sharing responsibility and making connections. The areas of development relate to outcomes around emotional wellbeing and being involved. It is worth noting that even though the themes from the pupilwise survey are similar for their overall peer group, these areas may impact differently on young carers due to their differing needs around their caring role.

Themes from Pupilwise:

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| --- | --- |
| Strengths | Areas for development |
| School help young carers to be safe on line, make healthy choices and provide opportunities to be physically active. | Better recognition of individual’s skills, interests and achievements, opportunity to give feedback on how to improve their learning and increase enjoyment. |
| Young carers report having friends they can go to or someone in school to go to if they are upset or worried. | Support adults to feel confident about supporting children’s emotional wellbeing. Enable young people to understand their own emotional wellbeing and how to keep well. |
| Young carers are aware of their rights and responsibilities. | More opportunities for young people to be involve in matters that affect them and to influence change and improvements in schools and communities. |

Summary

In total 134 young carers participated in the consultation in Fife to update the young carer strategy. The quantitative information provided via the online survey supports three out of the five emerging themes from the focus group discussions with slight differences noted in relation to impact on time with friends, impact on school work and having someone to talk to. The pupil wise survey results also supports the evidence provided via our consultation with young carers. The areas of strength and areas for development that emerged consistently mirrors the themes that emerged during the consultation. Based on all of this information the follow outcomes were highlighted as most important to young people at this time:

1. Sharing responsibility – *young carers will have access to appropriate support and information to allow them to continue in their caring role if appropriate to do so and access help that they need at a time that they need it.*
2. Making connections – *young carers will be able to access activities important to them, connect with other young people and develop friendships and relationships with people who understand them.*
3. Balancing time – *young carers will have the correct support to balance their caring role and time for themselves, including breaks from caring based on their individual needs.*
4. Being involved – *young carers will have access to quality information about their caring role and the person they care for and be seen as a valued expert in this role.*
5. Emotional wellbeing – *young carers will have access to correct support to help them deal with emotional side of caring and build resilience to cope.*

Receiving support for their caring role was rated as most important but how young carers prefer to be supported varies depending on their personal circumstances. Support to be prepared in an emergency was also rated important to young carers. A sense of responsibility was rated as a potential benefit of caring however this responsibility can also have the most significant impact in relation to feeling tired and worrying about the cared for person. Young carers care for people with a wide range of disabilities and illness and often care for more than one person in the household. Some young carers access support available and state that this is helping. They also have ideas about what else can be done, how to improve what we are offering and are asking for more of what works.

Future focus

* Continue to raise awareness and reduce stigma
* Support at an early age – primary school
* Promote positive post school destinations
* Promote emotional health and resilience
* Support breaks from care

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