

Individualised Funding

Guidance and Good Practice

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1. Introduction

Individualised funding (IF) is an administrative arrangement for some disabled people that enables them to hold, manage or govern their own needs-assessed budgets.

IF provides the opportunity for some disabled people to manage the personal support services they require in the way that they believe meets their needs best. It is an opportunity that, up to now, most disabled people assessed as needing support services in New Zealand have not been offered.

IF is not an additional service but is a development of existing services within current Disability Services Directorate policy and budgets.

This system requires that a disabled person possesses the competence and confidence to manage their own support budget. In certain circumstances a relative or appointed person may manage the budget on their behalf. In these circumstances the ‘budget manager’ will be assessed on their ability to manage for the disabled person.

IF has enjoyed a successful history over 20 years in many OECD countries. In general it has been applied to disabled people with degrees of disability requiring extensive or complex personal support requirements.

Around the world IF is not uniform in its application or scope.

- Some schemes exclude certain disabilities, and children or older people.
- Some schemes provide vouchers rather than cash in the bank to the IF budget-holder.
- There is a variety of forms of IF organisation ranging from voluntary and co-operative groups of disabled people to local municipalities and state-wide schemes.
- The funding used in IF schemes is from diverse sources: philanthropic foundations, state or federal funds and some is insurance-based.
- Some schemes are means tested.
- The numbers of disabled people participating in IF programmes vary from a few hundred to many thousands.

How IF works

In practical terms IF means that some people with disabilities will be able to hire, manage, pay, train and make their own contracts with their support workers or choose to manage aspects of this process. Such contracts are required to protect the employment rights of the support workers who are engaged. They will also ensure that the assessed needs to be met are addressed in the contract. The IF budget-holder is accountable directly, or more probably through a third party, for the budget they hold and its expenditure.

For the New Zealand version of IF – as in most programmes in OECD countries – there will be reasonable limits on the way the budget may be spent to provide personal support services. For example, such a budget may not be used to purchase major capital items such as a car. That would be considered a misuse of funds.

Should a request for an item outside the terms of personal support expenditure be made, there are other complementary channels of funding available. For example, this may apply to capital equipment such as a washing machine where incontinence is a problem or when adaptations to a home are required. Without exception, international surveys and comparisons have shown that the misuse of IF budgets is extremely rare.

Variations in IF, such as those of partial management of personal services, are available now even without a full-scale IF programme. For example, some individuals may wish to direct a support worker and manage their timetables but leave recruitment to an appointed and approved agent.

Support workers will generally be considered as ‘employees’ under IF. A support worker who considers they may have some other employment status will be advised to seek advice from an appropriate agency, for example, the Inland Revenue Department. The contract between the IF budget-holder and the support worker will reflect the employment status and be in accordance with all relevant legal requirements.

New Zealand’s proposed IF does not exclude any disability that is within the present scope of Disability Services. Physical, intellectual and sensory disabilities are all included. Mental health support is not included. For children, or for people with disabilities where there is cognitive impairment, there is the possibility of a parent, guardian or approved carer managing the assessed needs budget on their behalf. There will be provision in the IF programme for the services of independent, appointed advocates for the disabled person to be available.

Only some disabled people will wish to pursue the IF option. There are important administrative responsibilities that accompany taking on the task of self-managing support workers. These include tax, ACC, recruitment of support workers, training of those workers and contract requirements. There may be the difficult task of dismissing a support worker or of finding a new support worker if a valued and trained support worker leaves.

Many disabled people are satisfied with the level and quality of service they receive from direct providers and do not want the extra personal responsibilities IF brings. Others may be assessed as not able to manage a budget or support workers, even with the offer of an administrative framework that could underpin their IF choice.

In such circumstances the ‘intermediate’ opportunities between complete personal responsibility for self-managing the budget and direct service assume importance by maximising personal choice. For example, the direction of an agreed support package represents one way of exercising the greater control a disabled person might consider if not completely self-managing their personal support. This may happen where a disabled person expresses a preference for a particular support worker and particular times for the delivery of the support service.

New Zealand’s IF programme and the Disability Strategy

In New Zealand IF is congruent with the New Zealand Disability Strategy. It encourages people with disabilities to gain a greater measure of personal independence and play a greater role in the communities in which they live. The Ministry of Health, through its Disability Services Directorate, is ultimately responsible for funding and organising the framework of IF in New Zealand.

The Strategy's vision statement describes an inclusive New Zealand from a disabled person's perspective as 'a society that highly values our lives and continually enhances our full participation'. It means a country in which disabled people have a meaningful partnership with Government, communities and support agencies, based on respect and equality and a country in which 'disabled people are integrated into community life on their own terms. This means that equal opportunities are assured but individual choices are available and respected.'

2. IF in New Zealand Now and in the Future

Any history of IF in New Zealand to date is necessarily brief.

There are about 250 existing IF budget-holders in the country. Despite the fact that disabled people and their voluntary organisations had been pressing for an IF programme to be introduced for several years, the earliest coherent initiative to begin IF in New Zealand was at the end of 1998. It was organised by a combination of the (now defunct) Health Funding Authority and local Needs Assessment Service Co-ordination agencies (NASCs) galvanised by pressure from individual disabled people.

This Christchurch scheme began mainly because some disabled people repeatedly expressed dissatisfaction with direct service provision. What appeared to be an ‘all or nothing’ approach to meeting their needs was no longer acceptable to them. Most were younger people with assessed support needs that could not be met simply. For example, it would not just be personal assistance with showering or bathing that was required but with dressing, cooking, and helping in and out of bed and with toileting. That was one reason for the strong demand for self-management.

IF was not offered as a positive option but as a last resort. Though described as a ‘pilot project’, the valuable information it provided that could have helped form the basis for a national IF programme was, for a variety of reasons, never used.

Further unconnected developments of IF took place between 1999 and 2001 and IF now exists in a number of areas in New Zealand. There is, however, only limited overall consistency and sometimes a lack of safeguards in its provision. In some areas it was not offered or mentioned only as a possibility for disabled people by NASCs.

This lack of choice was compounded by the fact that the Ministry of Health itself had not authorised all NASCs to budget for discretionary funding of such schemes. The level of IF packages produced in different areas also indicated that meeting the greatest personal need through IF was not always the focus or starting point for new schemes.

As a result of this ad hoc development the Ministry imposed a moratorium at the end of 2001. This stopped any more IF until an equitable national framework with consistent, transparent and safe criteria for accessing it had been produced and agreed.

To achieve those aims and ensure they are monitored effectively this guidance book describes the creation and appointment of a new IF Agency (the Agency). It will work directly with NASCs, disability interest groups and individual disabled people.

The Agency’s work and the development of IF will be subject to evaluation. The Agency will be the result of a national Registration of Interest process to reinforce its autonomy in managing IF. However, it will be accountable for its activities to the Ministry and will be monitored through the Ministry.

Those disabled people who are presently holding IF budgets will continue to receive their present level of funding until the Agency has reviewed their circumstances in line with the approved guidelines.

3. Developing IF the New Zealand Way

It is among younger disabled people that the greatest demand for IF exists. It is among younger disabled people with complex needs that the success of IF arrangements by people making that choice of service provision will set the benchmark for future developments.

Focusing on what will be the most administratively demanding service provision during the initial two years of the IF programme will provide the best basis for assessing how effective the framework is. It will also determine what changes could or should be made to its future operation.

Consequently the Agency will begin the new IF programme outlined in this guidance book by concentrating on younger disabled people with needs that require a range of support service activities to meet them, described here as ‘complex needs’.

The role of the NASCs will be to provide the assessment service for this new IF programme. NASCs will no longer manage IF. All younger disabled people presently in receipt of IF will be reassessed and if they fulfil the IF criteria will become the responsibility of the IFA. This clearly defined approach to IF will provide the opportunity to establish a solid foundation to build on for evaluation and further development of the service.

The assessment of younger disabled people will be undertaken by the NASCs in line with current practice. Those applicants wishing to pursue the IF option, assessed as within the criteria and able to hold their own budgets, will be referred on to the Agency. They will have discussions about the nature of their budget-holding arrangements which the Agency will assist in setting up.

In line with the commitment made in the Health of Older People Strategy, introducing the option of IF for older people will be a matter for the Ministry and District Health Boards to consider when the two-year Agency programme has been evaluated.

Some older people also hold their own personal support budgets under the existing limited schemes of IF across the country. However, these IF arrangements are subject to the same inconsistent approaches and lack of safeguards as schemes for younger people. Consideration of those older people who currently hold IF budgets is the responsibility of the appropriate District Health Board.

The Agency will have two main functions. Firstly, it will support younger disabled people with complex needs who wish to manage their own IF budgets. Secondly, it will ensure comprehensive and consistent information, training and so on is available to NASCs, disability interest groups and individual disabled people. The aim will be to implement IF safely and equitably through monitored protocols and contracts for all those who exercise the option of managing their own support budgets.

Responsibility for ensuring there is a consistent contractual regime and proper financial accounting systems to support IF budget-holders will rest with the Agency.

A countrywide programme of IF has to take into account factors that could impact on its effective introduction. There are, for example, NASCs in the present arrangements with little or no expertise in or understanding of IF. Because of the NASCs' vital role in the assessment process there will need to be a training programme organised by the Agency for them before the launch of the IF framework.

Taking account of anticipated external change and bringing about internal change requires a degree of caution. So the programme to introduce IF to New Zealand is tempered by sensible caution. It will be a stage-by-stage programme. Everyone with a commitment to the Disability Strategy wants this programme to succeed and to become a major component in that Strategy's aim of making New Zealand a more equal place for people with disabilities. This guidance book represents a significant element in that process. It is based on the ideas and experience of disabled people, some of whom are existing IF budget-holders. Disability interest groups, NASC managers with experience of IF and other health sector professionals were also consulted.

4. Principles and Operational Rules

Principles underpinning the proposed IF programme for younger disabled people

The principles underpinning the scheme have been kept to a minimum, as have the operational rules governing its application.

- No disability is excluded.
- IF will be an option available for younger disabled people with complex care needs as a first step to a wider application.
- IF is not a personal entitlement.

Operational rules governing IF

- Becoming an IF budget-holder will follow an assessment by a NASC.
- Following full discussions and assessment, support arrangements as required will be organised by referral to the relevant IF support person at the Agency.
- The level of payment for service is to a maximum equal to the hourly cost of the individual's assessed support needs. IF does not generally apply to people living in residential care because such care is intended for disabled people who require fully supported, 24-hour care. There may be exceptional occasions when IF can enable a person to leave residential care, subject to a re-assessment of the individual's needs.
- A family/whānau member (or non-relative) may be approved to exercise the role of 'budget manager' for the budget-holder but payment for this responsibility is not permitted from the IF budget funds.
- In exceptional circumstances, a non-resident relative or whānau member may be employed to provide support services. For example, this would apply where the option of IF could not be accessed otherwise.
- At this time, assessed budgets may not be used to pay the partners of disabled people as support workers, nor may partners be paid for managing IF budgets. However, this is subject to the results of discussions between Government departments currently taking place and is expected to reach a report stage some time in 2004.

5. Assessments

Making IF an option for younger disabled people

Only younger people with complex needs are eligible for IF in this first phase of development. All referrals for service will, as now, go through a NASC. IF will be discussed between the NASC assessor and the disabled person as an option, along with all other service delivery arrangements including direct services and ‘intermediate’ arrangements such as self-directed care.

If the applicant wants IF to be considered, the NASC assessor will resolve with the applicant the complexity of needs and the ability to manage their own budget or, in certain circumstances, to have someone manage it for them. In this case the nominated ‘budget manager’ will be assessed on their ability to manage the IF budget.

Younger disabled people with complex needs will be referred to the Agency if they wish to take up the option of IF and are assessed as able to manage IF. The Agency will then discuss the preferred administrative framework required to enable the person to take up IF.

The disabled person may be referred back to the NASC for the provision of an alternative to IF. This may happen if they wish to revert to direct service after further discussion or, after a period of managing their own budget, they are not comfortable with the arrangements.

For older disabled people and for people with less complex needs the NASC will make arrangements in consultation with the disabled person to provide a choice of service options short of full IF. This will happen in accordance with NASC guidelines.

Setting and assessing levels of complexity

What are ‘complex needs’? There is an eligibility threshold that determines the complexity of an individual’s need and whether the IF option for service will be provided. Mention has already been made in the introduction to this guidance book of international comparisons. They have a use in defining New Zealand’s position in IF in terms of inclusivity and fairness, as well as positioning the New Zealand programme for future development.

The international IF schemes from which information was drawn included those in the UK, Canada and some countries in the European Union, and various state schemes in the USA. All differ to some extent in terms of who is in and who is out, the criteria applied and the levels of expenditure or service provided. However, there is no doubt that a sound assessment for IF undertaken with applicants is the key to a successful IF programme.

Assessing need is not an exact science but there are indicators that will reduce the potentially arbitrary and subjective nature of the assessment process. The most successful and satisfactory assessments also integrate the views of the person assessed. It is particularly important in IF assessments that they are not ‘done on’ people but with them.

Setting New Zealand's IF needs threshold

The new programme in New Zealand is intended in the first two years for younger people with complex needs. The assessment will include personal, environmental and social risk factors in the level of support needed. Such factors include the ability to perform basic tasks, communication, mobility, getting in and out of bed, cooking, washing, dressing and so on, and the availability and extent of existing support systems.

There are other factors that also have a bearing such as family/whānau support and social or geographical isolation.

The existing NASC guidelines for assessing high needs will be adopted as the means for assessing IF for younger disabled people with complex needs. Included in the needs assessment will be an evaluation of the ability and determination of the disabled person to take on the IF responsibilities.

In one international model the level of ability required to understand and be aware of the responsibilities of IF is high. People with intellectual disability are therefore excluded and so are children. The New Zealand proposal excludes neither. Experience has shown that the management of an IF budget can successfully work through a family or trust on behalf of an individual. Consequently the understanding required by the disabled person does not need to be set so high in some circumstances.

Assessment guidelines: helping disabled people make their choice

As IF will no longer be a last resort for disabled people who have had unsatisfactory experiences with other service provision, it will be presented in an equal way. However, the IF option at this stage is only for younger disabled people. If someone does not fulfil that basic requirement then there will be no discussion of IF.

It should not be assumed that the whole process is too difficult for disabled people. Even when IF was on offer as a second-best option, those who took it up have in the main succeeded in managing their own budgets, sometimes in the absence of a supportive framework.

The new framework and criteria should enable younger disabled people to take up IF in a safer environment. NASC assessors must initially discuss with disabled people they are working with what is and what is not advantageous about IF. The information they share with the applicants will be as clear as possible and provided by the Agency on a national basis. The NASCs will then refer on younger disabled people with assessed complex needs to the Agency if their assessment points to IF as the right course.

The new element in the assessments is to look at the ways in which support systems can be applied to enable someone who is eligible and wants to exercise the IF choice to do it. The task is to accentuate the positive and reduce the negative where that can be done safely within the framework and guidelines of the new scheme.

There are various potential ways for the administrative support arrangements to be made that may be required by some IF budget-holders. It could be a national approach. Alternatively, it could be that local solutions tailored to fit individual preferences would be arranged. Given that

the latter arrangements pre-moratorium were entirely localised and mostly effective, there is no reason to believe that the new national scheme could not be locally based.

If local arrangements are the preferred option it will be the responsibility of the Agency to find individuals, companies or voluntary organisations that would take on the administration of IF budgets, for example, invoicing, tax and ACC payments, for budget-holders who do not want or do not feel confident to handle them. Such a service will not be free to the IF budget-holder; it will be paid for by the budget-holder, though allowance for such costs will be included in the person's IF budget.

It is expected that the close working relationships between the Agency, NASCs and disability groups in each region will provide for the exchange of information on networks and community services that will enhance the options available to IF budget-holders.

Existing younger disabled IF budget-holders are an indication – though not an accurate cross-section – of who may be expected to manage, or have someone manage, their own needs assessed budgets. There are physically and intellectually disabled people among these budget-holders.

There should be no sense that IF budget-holding is a 'once and for all' commitment. Just like anyone else disabled people may change their minds or find their circumstances have changed. They need to know they can receive direct services if they stop IF budget-holding.

The first requirement of a NASC assessment is therefore to avoid making assumptions about anyone's ability prior to full assessment and discussion. The second is to provide the fullest information about the advantages and the difficulties of handling a budget or handling one on behalf of someone else.

At this stage some people will decide IF is not for them because it involves too many worrying aspects and potential uncertainties. For those who wish to pursue the IF option, discussion should centre on what the disabled person believes to be the most difficult aspects of managing their own budget. The assessor should be able to provide a view with the intention of reaching a solution satisfactory to the IF applicant of how far those concerns can be met by administrative support.

There are some obligations on the IF applicant that must be discussed. IF will not proceed unless there is agreement by the applicant to accept them. For example, someone hired as a support worker, but without any training or experience to perform personal care tasks, should receive some basic training. That might prove to be a stumbling block if there were a reluctance by the IF applicant to be persuaded of the value of such training.

Another example, if the applicant was unwilling to accept that contracts with support workers were essential then IF would not take place. Of course, the vast majority of IF budget-holders will see these obligations as necessary and important in providing greater security to them and their support workers.

The discussions, interviews and information are intended to inform the decision of the disabled person about whether or not IF is for them. It should be a very rare occasion when, within the framework described, an assessor takes the view – against the wishes of the disabled person – that they are not capable of managing their own budget, staff and services. In the main, the disabled person will be the one who makes the decision about whether or not IF is what they want and can manage.

On those occasions when the results of an assessment appear to indicate a negative response to an IF application, NASC assessors should be prepared to say why this is so. Here are a couple of real examples.

If the attitude and behaviour of a male disabled person created problems for female support workers, then unless he could recruit male support workers an assessor would legitimately have doubts about his IF budget-holding capacity.

Bouts of repeated ill health, even though the disability remained stable, could make the IF untenable and possibly place the IF budget-holder at risk.

In these circumstances, as in any others where a refusal of IF is considered reasonable, the applicant should be given a full explanation. If this is not agreed to by the IF applicant (or an applicant budget manager on their behalf) then a re-assessment will be provided by the NASC using a different assessor. If this proves unsatisfactory to the applicant then as a final step a further assessment may be requested and provided by another NASC. There are no further stages to follow within the IF process should this also prove unsatisfactory.

6. Working Together to Achieve the National Programme

The IF Agency and its responsibilities

The Agency has as its primary function responsibility for arranging and supporting IF for younger disabled people with complex needs following a referral by a NASC.

It is established to ensure the application, implementation and monitoring of a safe, fair and consistent IF framework and criteria across the country.

The Agency will:

- work regionally with NASCs and disability interest groups
- provide all NASCs with the training, information, protocols and the contractual framework necessary to assess and support younger disabled people for IF within the national framework
- monitor the progress of NASCs in implementing their assessment role in IF
- arrange for younger disabled IF budget-holders with complex needs any administrative framework should that be required by the individual to manage their budget
- be responsible for ensuring there are contracts between all IF budget-holders and their support workers
- arrange training as required for all budget-holders and support workers including advice on recruitment, managing budgets, managing staff and basic household safety
- ensure there is a written back-up plan in case of sickness or absence by the budget-holders' regular support workers
- monitor the progress of IF budget-holders through regular follow-up contacts and visits
- arrange for the provision or re-provision of direct services with the NASC should an IF budget-holder request it, or a re-assessment shows it is necessary
- produce a recommended transitional process for IF budget-holders who leave the scheme
- ensure close working relationships at a practical level, for example, sharing information with NASCs and disability groups about local supportive networks
- monitor through a formal three-monthly questionnaire the work of the NASCs on initial referrals and other matters such as the appeal and review processes for disabled people who are dissatisfied with decisions made in their IF applications.

Training responsibilities of the Agency

The Agency will have the capacity to let contracts to provide for the different types and levels of training required by an IF budget-holder or support worker, as and when such training becomes necessary.

Training will be organised by the Agency for those disabled people who take up the option of full IF in how to manage budgets, staff and the recruitment process and in such matters as tax, ACC and other administrative matters relating to their role as employer.

For the support workers employed by high-needs IF budget-holders, basic training will be organised by the Agency where required, for example, in lifting, moving and bathing people. Budget-holders may request other appropriate training for their support workers.

This training and direction is intended to prevent IF drifting back into being an occasional, localised service. It is also a vital part of making the new programme truly national, consistent and safe.

The NASCs and their responsibilities

Needs Assessment and Service Co-ordination will continue to be the access point for services for disabled people. However, the equal status of IF as a service choice means that there has to be considerable change in the way information about service delivery options is presented to younger disabled people. Such information will clearly set out the advantages and disadvantages and the responsibilities of IF.

Once a NASC has assessed the needs of a younger disabled person, their wishes concerning IF and levels of complexity of need, and concludes that IF is right for them, the NASC refers them on to the Agency. The Agency will then arrange IF in the most supportive way for that individual.

If, after assessment and referral, there is a change in that situation, and direct services or some arrangement less than full self-management would be more appropriate, the applicant returns to the NASC for suitable arrangements to be made to support the decision.

For IF budget-holders with the Agency who decide or become unable to continue to be budget-holders, the NASC will be responsible for organising appropriate alternative services.

For younger disabled people with complex needs who are already in receipt of services but wish to consider a move to IF, the NASC will be responsible for assessing them based on the threshold definition of complex care. There will also be an assessment of the ability of the individual to hold their own budget or have it managed for them.

The IF budget-holders and their responsibilities

IF budget-holders are not just service recipients. They are responsible for the good management of those who work for them, for proper payment arrangements of those support workers and for the exercise of good employment practice in accordance with relevant laws and other regulations.

IF budget-holders must:

- ensure they observe tax, ACC, sick pay and holiday pay rules and regulations and should make sure they have proper administrative support if they do not wish to do these things. They will have to pay for such services, though an allowance will be included in their budgets to help with these costs. The Agency will ensure that, where needed, such arrangements will be in place
- accept training in managing staff and fulfilling contracts whether they are wholly managing their budget or not

- accept that where they have personal needs, including the need for bathing, lifting and so on, their support staff will be obliged to receive basic training which the IF budget-holder will be able to define and direct
- work out with the Agency a back-up plan in writing for occasions on which their support staff may be unavailable
- make sure they have an up-to-date contract with each of their support workers available to the Agency if required, and notify the Agency of any significant change in their circumstances.

The Disability Advisory Group and its responsibilities

A Disability Advisory Group will be established to help fulfil one of the Government's defined objectives in the New Zealand Disability Strategy. That objective is to 'foster leadership by disabled people, acknowledge the experience of disability as a form of specialised knowledge and strengthen the leadership of disabled people'.

- The Manager of the Agency will be expected to hold regular meetings with the Advisory Group.
- The Group will consist of representatives of national voluntary disability groups representing physically and intellectually disabled people.
- There will be encouragement to make connections by establishing branches in the regions with representatives of the Agency in those branches.
- The detailed terms of membership for the Disability Advisory Group will be the responsibility of the IFA, but the Group will have a rotating membership to allow for the inclusion of as wide a cross-section of disability organisations as possible.